Families of the Traumatically Brain-injured: A Case Study Approach to Perceptions of Quality of Service, Degree of Satisfaction, and Family Needs

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St. Catharines, Ontario

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Abstract

The purpose of this qualitative research study was to foster an understanding of the rehabilitation counselling practice of families of the brain-injured. Specifically, the study explores the perceptions of stakeholders in regards to the degree of satisfaction with the quality of service received. Questionnaires were administered, and semi-structured, open-ended interviews were conducted, with six participating families (n=8). Preliminary data were collected via two instruments: (i) the Family Participant Questionnaire, consisting of participants' sample characteristics, information pertaining to the history of the family, details of the injury, and information relating to the type, use, and need of family services utilized; and (ii) the Community Integration Questionnaire, a measurement of the degree of social displacement/level of community integration of the injured family member.

Utilizing the procedural steps outlined by Colaizzi's (1978) method of protocol analysis, recommendations for a future program based on related and current family needs are discussed in detail. Substantiating and supporting information are offered to rehabilitation practitioners, educational planners, and policymakers alike, concerning the degree of satisfaction with rehabilitative service, and the means of improving upon the overall quality of health care to families of the brain-injured. Implications for clinical practice and research are also raised for discussion.
Dedication

To my wonderful spouse, Grant, who fills my heart with joy, expands my mind, and lifts my soul to new dimensions with his unwavering love, kindness, and inspiration. May you continue to shed a ray of sunshine on the blossoming tree of our lives, always! To my parents, one of the most primary gardeners of my personal development, whose endless love, caring, and nurturance, shed a ray of sunshine on the flower of my youth. And to my wonderful family and friends for believing in me, and fostering the patience, determination, dedication, and perseverance needed for successful completion!
Acknowledgements

I would like to acknowledge several individuals who were instrumental in the completion of my thesis. A very special thank-you is extended to Dr. Terry Boak, my thesis supervisor, for his intelligent advice, consistent and dependable guidance, kind concern, and gentle way of guiding me forward.

I also wish to extend my sincere appreciation to my thesis committee. I thank Dr. Raymond Chodzinski, Dr. Don Dworet, Ms. Caron Gan, Dr. Michael Kompf, and Dr. Cecilia Reynolds, for their constructive feedback and valued expertise.

I would also like to thank the many professionals in the brain injury rehabilitation field with whom I discussed this research, including: Dr. Alan Finlayson of the Chedoke-McMaster Hospital; Ms. Caron Gan at the Hugh MacMillan Rehabilitation Centre, Toronto; Dr. Barry Wilier of the Brain Injury Association of Ontario, and Ms. Ruth Crawford and Ms. Esther Vetter of the Head Injury Association of Toronto.

I am also indebted to my key contacts at the various organizational sites consulted for recruitment purposes. My committee and I have elected not to name these individuals and their respective organizations in order to protect their identity and ensure anonymity. Your time and efforts put forth during the entire recruitment process were much-appreciated. Thank you all for your unfailing support and willingness to recruit study participants.

A very special acknowledgement is extended to all caregivers and their families who were willing to share their experiences and feelings so openly with me. Thank you infinitely for your valued time and participation!

I am also very thankful to my proofreader, Ms. Eileen Kraatz, for her valuable time spent reading the manuscript, and for her countless thoughtful comments and suggestions.

To Drs. Ardra Cole and David Hunt, for their wonderfully supportive and insightful book of reflections of the doctoral thesis journey. Their words of wisdom inspired me to move my work along by visualizing my thesis as a beautiful tapestry-in-process. Their collection of reflections also gave me the courage to pursue this journey of
self-knowledge and understanding, to risk taking the trip into an unknown, ambiguous, uncertain, and sometimes isolating abyss.

Most especially, my profound love and appreciation to my husband, Grant, for rooting, inciting, boosting, prodding, egging, and cheering me on. A very special acknowledgement is given to you, Grant, for celebrating all of the tiny accomplishments, every step of the way!
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<th>SAMPLE CHARACTERISTICS</th>
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Frequency Counts of Sample Characteristics

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<tr>
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<td>- Social Worker</td>
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<td>- Hospitals</td>
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<td>- Psychologist</td>
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<td>- Social Worker</td>
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<td>- Rehabilitation Centres</td>
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<td>- Review of head injury literature</td>
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<td>- Voluntarism in rehab field</td>
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</tr>
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<td><strong>OTHER</strong></td>
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<tr>
<td>- Talks with psychologist</td>
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<tr>
<td>- Informal supports, (ie., friends, family, religious affiliations, neighbors, etc.)</td>
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(Table continues)
### Table 2 (continued)

**Frequency Counts of Sample Characteristics**

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<th>RELATIVE FREQUENCY</th>
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<td>Traditional (Nuclear family: both parents &amp; their children)</td>
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<td>Non-traditional (Single parent)</td>
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<td><strong>Kinship of Caregiver in relation to injured individual</strong></td>
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<td>Parent of injured child</td>
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<td>POST-INJURY:</td>
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<td>Less close</td>
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<tr>
<td>Brain-injured individual lives with caregiver</td>
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<tr>
<td>Brain-injured individual lives independently</td>
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<td>Cyclist struck by an automobile</td>
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<td>Work-related accident</td>
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*Discrepancies in totals are due to rounding to the tenth decimal.*
"We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time."

T.S. Eliot, "Four Quartets"
CHAPTER ONE: THE RESEARCH PROBLEM

Introduction

The purpose of this qualitative research study was to foster an understanding of families of the brain-injured's perceptions concerning the degree of satisfaction with the quality of service received. Additionally, its aim was to identify whether or not there are any gaps in service provision, and solicit recommendations as to how to improve upon the overall quality of health care to the target population.

Background of the Research Problem

As a close family member of a brain-injured loved one myself -- and as a rehabilitation consultant who provides counselling and case management services for those who have sustained injury as a result of a motor vehicle accident -- I, along with various brain-injured individuals, family member cohorts, and members of various rehabilitation firms, hospitals, and associations, have held concerns about the quality of service being provided both to survivors and family members following the brain injury of a loved one.

When our devastating family tragedy occurred nine years ago, I sadly observed that there was a lack of adequate community resources and support for the brain-injured population in general. More particularly, there seemed to be even less available in the way of government or non-profit sponsored programs for family counselling and support services. Stambrook, Peters, and Moore (1989) have substantiated these personal observations, indicating that, "The consequent result [of brain injury rehabilitation] has
3. Determine the appropriate data storage structure used for the proposed model.

4. Implement a comprehensive testing strategy to validate the model's performance.

5. Evaluate the model's effectiveness in real-world scenarios, ensuring robustness and reliability.

6. Document all findings and results for future reference and potential improvements.

7. Conduct a thorough review of the literature to ensure the novelty and relevance of the proposed approach.

8. Discuss the limitations and future directions for further research based on the current findings.

9. Share the research outcomes through publications, conferences, and other academic platforms.

10. Foster a collaborative environment with other researchers and practitioners in the field to advance the state of knowledge.

In conclusion, the proposed model offers a promising approach to solving the challenges faced in the field. Further investigation and validation are necessary to fully realize its potential. The research community is encouraged to contribute to this exciting area of study, building on the foundations laid by this work.
been a saving, and then a prolonging of life, but with little attention paid to the quality of
such life, that which most profoundly affects patients, their families, and the social
network they are immersed in" (p.87). In a similar vein, Kreutzer, Zasler, Stiles Camplair,
and Leininger, cited in Finlayson and Garner (1994) have argued that feelings of grief,
fear, and exhaustion are complicated by frustrations arising from the lack of community
services. These researchers have confirmed that the development of rehabilitation
programs for community integration has seriously lagged behind the development of acute
rehabilitation and neurosurgical intervention.

Other bodies of research have additionally confirmed the need for increased
services to families of the brain-injured. Florian and Sachs (1991) contended that greater
attention in the brain injury rehabilitation field is now focused on treatment specifically for
families of the brain-injured, insinuating that, prior to 1991, such services did not exist.
Similarly, Jacobs (1985) documented that families constitute the major source of support
for the brain-injured individual. Finally, Kozloff (1987) explained that families may take
on more responsibility for support activity than any community agency or facility,
particularly over the lifetime of the survivor after institutional care is no longer provided.
The medical model places the brain-injured individual at the heart of treatment while
family members attempt on their own to deal with a broad gamut of tumultuous changes,
in a piecemeal fashion via trial and error, and to the best of their abilities. This gamut
includes, but is not limited to the following: the repercussions of the injury to the brain-
injured individual, the brain-injured individual's recovery and adaptation to disability,
issues surrounding successful rehabilitation, family members' grief behaviour, coping
mechanisms and adjustment to loss, as well as changed family roles, relationships, and dynamics.

Although hospitals do educate family members, and provide some limited emotional support at the acute stage, opportunities for ongoing education and support become severed at the point of discharge from hospital. Programming in the acute, post-acute, and adjustment phase did not, in my opinion, effectively prepare our family for the unique challenges which lay ahead. Indeed, it is commendable that in the twentieth century, medical science has developed the sophisticated technology required to successfully resuscitate individuals with brain injury where, prior to such developments, they would quite simply die. It is, however, critical that the field of rehabilitation medicine simultaneously reflect upon after-care, quality of life, vocational, and family issues. It is my belief that, as concerned and responsible health care professionals, consumers of health care, and other interested parties, we should take a more proactive stance with regards to demanding services which would assist this target population in the adaptation process. I therefore believe that there is a need to examine the quality of existing programming, as well as plan and implement needed community resources for families of the brain-injured. Families not only require such assistance in their adjustment process to head trauma; more importantly, they are deserving of such assistance by virtue of the severe physical, cognitive, emotional, and behavioral deficits which occur as a result of traumatic brain injury (Grinspun, 1987).

It is widely acknowledged in the literature that the family, like their brain-injured loved one, faces tremendous difficulties and challenges in their adjustment and adaptation
to traumatic loss (Davis, 1988; DePompei, Zarski, & Hall, 1987; Lezak, 1986, 1988; Schwentor & Brown, 1989). The sudden alteration of lifestyle, and the onerous demands imposed upon family members, following the onset of a loved one's head trauma, have profound and devastating effects upon the family members' lives, roles, interaction patterns, dynamics, and family structure. Additionally, the traumatic brain injury of a loved one is a major family stressor since it places onerous demands and challenges upon family members (Perlesz, Furlong, & McLachlan, 1992; Pessar, Coad, Linn, & Willer, 1993). Hence, since family changes incurred as a result of brain injury can be severe, functionally significant, and prolonged, family needs and quality of service should be investigated, reviewed, and evaluated on an ongoing basis.

Although The Canadian Association of Rehabilitation Personnel and other similar organizations are developing new professional standards for service delivery, a review of current literature was unsuccessful in locating research that has been conducted regarding brain-injured families' level of satisfaction with existing service. Accordingly, a more general review of the etiology, epidemiology, and pathobiology of traumatic brain injury was initiated, in addition to a comprehensive review of its impact upon the family system. Furthermore, a review of the identification of the needs of families of the brain-injured and needs assessment literature was also undertaken, followed by an introduction to the concepts of rehabilitation and rehabilitation as a service. To understand families' degree of satisfaction with the quality of service offered to this particular client base, the review informs us about literature relating to quality of service and satisfaction, both in general terms and as these relate specifically to traumatic brain injury programming for families of
the brain-injured.

The Problem Statement

This qualitative study explored the experience of brain-injured families with respect to degree of satisfaction with the quality of services rendered. Second, as a phenomenological study, it aimed to enhance the researcher's understanding of family needs through a description and interpretation of the social context (Rothe, 1993). Third, the study aspired to expound recommendations as to how to improve upon the overall quality of health care to the target population.

Purpose of the Study

The purpose of this study was threefold. Firstly, the study endeavoured to obtain verbal information from families of the brain-injured regarding their degree of satisfaction with the quality of existing service. In this regard, its aim was to foster an understanding of current satisfaction levels with a view to identifying whether or not there were any perceived gaps in the delivery of service. Secondly, this piece of research purported to gain an understanding of the target population's unique family needs, which might in turn be incorporated into a future education programme for families of the brain-injured or otherwise assist educational planners and administrators in improved service delivery. Thirdly, the study endeavoured to obtain comments from family members as to how to
to understand the nature and significance of the concepts involved. It is important to note that the

text provides a detailed explanation of the relevant ideas and their implications. The examples

given in the text serve to illustrate the practical applications of the theoretical concepts discussed.

The text concludes by emphasizing the importance of continued research and the need for further

evaluation of the findings presented. It is hoped that this work will contribute to a deeper

understanding of the subject matter and pave the way for future advancements in the field.
improve upon the quality of service.

Rationale

Traumatic brain injury wreaks havoc upon its many victims: individual survivors, immediate close families, friends, and extended families (Lezak, 1988). Indeed, one may argue that in a broader sense, society, too, stands victimized by the loss of productivity, loss of enjoyment of life, and loss of economic viability that a severe head trauma almost always brings. After all, an invasive assault to the brain -- invoked by a motor vehicle, industrial, or sporting accident -- may ravage one's personal, professional, and social life.

Given the significant and pervasive changes which occur in the family's adjustment process, and in order to more fully appreciate the scope and complexity of such challenges, I chose to investigate families' degree of satisfaction with the quality of service offered to the target population. An understanding of families-of-the-brain-injured's degree of satisfaction with the quality of service offered, report of current needs, and recommendations for a future program based on related and current family needs may:

- Reduce family burden and stress following the onset of a traumatic brain injury of a loved one;
- Improve family relationships and foster open communication channels;
- Facilitate healthy family adjustment to traumatic loss as a lifelong process;
- Enrich the family's coping mechanisms and resources;
- Positively impact upon the adjustment and recovery of the brain-injured family members;
Improve communication channels between service providers and clients;

Ameliorate the quality of health care available to families of the brain-injured;

Minimize any ineffective or inefficient practices in the service delivery system to the target population, promote greater cost-effectiveness, and improve use of clinicians' time;

Promote higher degrees of satisfaction regarding quality of service delivery.

In view of this comprehensive list of outcomes resulting from the systematic investigation of families' needs and, ultimately, the understanding of families' perceptions concerning quality of service, it is imperative to determine whether or not rehabilitation practitioners are attending to the issue of how to effectively meet families' needs.

**General Research Interests**

It is important to note that I entered the research process shaped by a myriad of experiences, all of which coloured my frame of reference and looking-glass. As a former customer relations agent for a number of large multinational organizations, I was trained to espouse a keen sense of client-commitment, service orientation, and commitment to quality and excellence. As a family member who grappled firsthand with the trying and devastating effects of brain trauma, I was seeking a personal, emancipatory way to make meaning of the traumatic event. As a relatively new helping professional in the field of rehabilitation psychology, I was keenly aware of the need for improvements in the quality of health care to individuals with special needs. Finally, throughout my learning journey as
a graduate candidate, I had felt exhilarated by the numerous opportunities for significant personal growth and development, and driven by my boundless intellectual curiosity, energy, and inner resourcefulness.

With this plethora of "goods," it was therefore natural to enter into the research process with numerous questions. It was also natural that I should wish to consolidate my experience into a work that would have high personal relevance and meaning. Inasmuch as my general research interests assisted me in exploring questions related to content and process, understanding of family needs, quality of service provision, perceptions of satisfaction, and learning methods/outcomes of service delivery, it is important to note that such questions were not intended to guide the data collection process. The intent in making them explicit is to be open in revealing my preconceptions as a researcher, and to provide some initial boundaries for the investigation.

1. How does Rehabilitation Counselling practice develop an understanding of families' needs? How does Rehabilitation Counselling practice negotiate quality of service issues with families-as-clients?
   (a) What is the process?
   (b) Who defines activities and whose perspectives dominate?

2. How do the families-as-clients and therapist experience one another?
3. How do rehabilitation practitioners provide service? What measures are taken to evaluate service provision to families of the brain-injured?

4. How do families experience their rehabilitation providers? What are their perceptions concerning professionals' ability to service needs?

5. How similar/discrepant are the families' perceptions in regards to satisfaction? How do the "personal" and "professional" realms meet?

6. Are the needs of families-as-clients being met? If not, what components of service are missing links?

7. If we could provide an outstanding service to families of the brain-injured, what would such a service include/encompass?

8. What are the intended learning outcomes of service delivery to this population? What are the perceived outcomes?

The following specific research questions, by comparison to the broader, conceptual issues underlying the general research interests, were intended to guide the data collection process. In order to elicit a rich and full understanding of the essence of families' experience with rehabilitation counselling practice, I wished to investigate the
following research questions, specifically:

**Research Questions**

1. Describe what you feel about the quality of family services you received following your loved one's brain injury. How satisfied are you with the family service you have received?

2. What, if any, gaps are there in the delivery of service? What are your family's present needs as a result of the traumatic brain injury of your family member?

3. What are your recommendations as to how to improve the quality of service to families of the brain-injured? How might rehabilitation practitioners incorporate these into a future program for families of the brain-injured?

4. What are your feelings concerning the quality of service you received at various stages of your adjustment: (i) immediately upon onset of trauma; (ii) when your injured family member underwent rehabilitation, and (iii) when he/she entered the community or home again?

5. What did rehabilitation practitioners do that you found helpful/unhelpful in coping?
6. What is important to you when you receive education, counselling, or support services as a family member?

7. What components of service did you find most/least helpful?

8. How satisfied were you by the way in which rehabilitation practitioners communicated with you? Did you feel heard and listened to?

9. How available were these professionals to assist you?

10. How accessible were the services? How did you find out about the services utilized?

**Definition of Terms**

**Traumatic Brain Injury:** Any trauma to an individual's head that results in some degree of physical, cognitive, affective, and sensorimotor impairment (Grinspun, 1987).

**Family Member/Primary Caregiver:** Individuals 18 or older, who (i) assumed primary responsibility for caring for a family member with a brain injury in the home, (ii) who identified themselves as being most informed and knowledgeable about the health and social circumstances of their injured family member, and (iii) who had received family
support services through the four research sites selected for recruitment purposes.

It is important to note that the term "families" is commonly utilized for greater ease of presentation, though the focus of the study is on primary caregivers and not families, per se.

**Scope, Delimitations, and General Assumptions**

It is important to be aware of the study's preconceptions and major influencing assumptions in order to understand the nature and the limits of the emergent knowledge. To comprehend the specific conceptual limitations of this undertaking and acknowledge their existence, it was necessary to examine the various ontological, epistemological, and axiomatic presuppositions inherent in research methodology. Importantly, an understanding of the philosophical underpinnings of the study offers a context upon which to view the research, thereby fostering in readers an appreciation for the intricate dialectics and rich heritage to which this study pays tribute.

Research in the behavioral sciences generally falls into one of two realms: the natural sciences (i.e., empirical-analytical quantitative research) or the interpretive and critical sciences (i.e., qualitative research). According to Rothe (1993), ontology literally means the study of being, reality, or existence. In quantitative research approaches, reality is construed as objective, real, observable, and separate from the individual (Cole & Hunt, 1994; Lather, 1986a, 1988; Rothe, 1993). The qualitative research paradigm, however,
proposes that reality is subjective, constructed, interpreted, and, therefore, integral to the individual.

Just as metaphysical preconceptions differ in the natural sciences, as compared to the critical and interpretive sciences, so, too, does their epistemological stance. Epistemology literally means theory of knowledge; it concerns itself with the issue of how we know what we know. The epistemological tenet of quantitative researchers is that knowledge is a product of rational thought. By comparison, qualitative researchers hold that knowledge is the product of opening up to our senses and perceptions in order to gain access to rich and meaningful understanding (Cole & Hunt, 1994; Lather, 1986a, 1988). While in the natural sciences there is a focus upon manipulation and control of the environment and prediction about observable events, in the interpretative and critical sciences there is a focus upon description, understanding, and meaning-making (Cole & Hunt, 1994).

Finally, investigators differ in terms of their precepts regarding what is valuable. The study of axiology or ethics concerns itself with this precise question. For quantitative investigators, establishing causal connections or predicting human behaviour is desirable; for qualitative researchers, describing, understanding, or interpreting carries greater value. Hence, an understanding of the various ontological, epistemological, and axiomatic presuppositions inherent in research methodology plays an important role in allowing readers to recognize the specific conceptual limitations of this undertaking, and to acknowledge their existence.
The study was also naturally influenced by the fundamental assumptions I hold. The assumption that propelled and influenced this entire work was that the quality of health care available to families of the brain-injured can and must be improved. Secondly, I hold as a basic tenet that services to families of the brain-injured, or other client groups, need to be client-centred and client-driven; that is, clients need to be encouraged to express their opinions concerning the manner in which they wish to be serviced. Otherwise stated, consumers of services should be given opportunities to provide input about changes to be made (Bailey, McWilliam, Winton, & Simeonsson, 1992). Thirdly, given that family changes incurred as a result of brain injury can be severe, functionally significant, and prolonged, the final assumption which provided the impetus for this work lay in the belief that family needs and quality of service should be investigated, reviewed, and evaluated on an ongoing basis.
CHAPTER TWO: LITERATURE REVIEW

Introduction

The literature review is a critical examination of the published body of literature relevant to the study under investigation. Its purpose is to inform both myself, as researcher, and readers as to the fundamental concepts that are central to a particular research study. To sculpt a context for this research study, therefore, I have drawn upon similar studies, compared them, and determined their potential in broadening our current knowledge-base and levels of understanding.

This chapter is comprised of five broad sections, the first of which begins with a general review of the etiology, epidemiology, and pathobiology of traumatic brain injury. Incorporated into this section is a discussion of the pervasive and wide range of deficits and limitations that emerge following the onset of brain injury. To foster an understanding of the rehabilitation counselling practice of families of the brain-injured, the second section focuses upon an introduction into family issues, and the impact of traumatic brain injury upon the family system. The third section reviews literature pertaining to family needs and needs assessment, while the fourth section examines the theoretical framework of rehabilitation counselling, and introduces the concept of rehabilitation as a service. Finally, to understand families' degree of satisfaction with the quality of service received, and enhance the understanding of current family needs, the review focuses on literature relating to quality of service and satisfaction as these relate specifically to traumatic brain injury programming for families of the brain-injured.
Etiology, Epidemiology, and Pathobiology of Traumatic Brain Injury

Introduction to the Concept of Traumatic Brain Injury

"The prerequisite in studying a disease is its definition" (Frankowski, cited in Peterson & O'Shanick, 1986, p.153). In their epidemiological study, Kraus, Rock, and Hemyari (1990) defined brain injury as "physical damage to, or functional impairment of, the cranial contents from acute mechanical energy exchange, exclusive of birth trauma" (p.684). Similarly, other research has defined brain injury as acute physical damage of the brain, skull, dura, scalp, or face, caused by external mechanical energy (Frankowski, cited in Peterson & O'Shanick, 1986). In their prospective study carried out in Bordeaux, France, Cohadon, Richer, and Castel (1991) defined head injuries as contusions, lacerations, skull fractures, or brain injuries, and/or loss of consciousness following head impact.

Although the traumatic brain injury literature suffers from inconsistencies in the scope and definition of brain injury (Kraus et al., 1990; Snow, Macartney-Filgate, Schwartz, Klonoff, & Ridgley, 1988), there seems to be considerable agreement concerning the degree of morbidity that brain injuries incur. Fortunately, the majority of brain injuries, (i.e., contusions, lacerations, or simple fractures) are inconsequential to the individual. In these cases, the brain-injured individual recovers uneventfully, without significant sequelae. Other injuries, however, threaten the organic integrity of the brain and result in serious morbidity. Injury to the brain may cause significant and possible irreversible neurological, neuropsychological, or functional impairments (Frankowski, cited in Peterson & O'Shanick, 1986).
Deficits and Limitations following Traumatic Brain Injury

In this section of the literature review, the researcher and readers are informed of the pervasive and wide range of deficits and limitations that emerge following the onset of brain injury. According to Grinspun (1987), the brain-injured individual faces difficult, and sometimes insurmountable, challenges in dealing with a wide range of deficits and limitations. This range includes, firstly physical or sensorimotor disability characterized by difficulties with mobility, balance, movement, and coordination. Secondly, the survivor of head trauma may experience communication deficits; communication may be compromised by deficits of speech, language, or cognition.

A third type of limitation was described by Grinspun (1987) as cognitive-perceptual deficits. These include deficits of memory, information processing, sequencing, planning and organization, learning ability, perception, and conceptual and executive thinking. Of note, according to Grinspun (1987), is the cognitive component since difficulties in this area can pose as tremendous barriers for renewed family life, productive employment, and "normal" social interaction. Finally, a fourth limitation for the brain-injured individual lies in behavioral changes. It is not uncommon for brain-injured survivors to exhibit aggressive behaviour, restlessness, impulsiveness, poor judgement, and decreased insight or awareness of deficits. The combined effect of these multiple deficits following traumatic brain injury creates tremendous psychosocial consequences for the brain-injured and their families.

Likewise, Lezak (1988) argued that most brain-damaged individuals suffer from two different kinds of behavioral disturbances. Both result in behavioral and emotional
alterations in personality. The first is characterized by difficulties with self-control and executive functions, and can be understood as direct consequences of injury (Lezak, 1988). Admittedly, as the severity of the organic damage increases, the capacity for self-awareness, and particularly for accurate self-perception, decreases. At the other extreme of the spectrum are persons who sustained little tissue damage. Although their capacity for self-awareness has remained virtually intact, and they have experienced minimal emotional and personality alterations on an organic basis, these clients are aware of their reduced mental efficiency and related impairments. Such awareness frequently causes anxiety, irritability, or social withdrawal. For this reason, the psychological disturbances of these mildly impaired patients are indirect consequences of brain damage. Lezak (1988) argued that most brain-injured clients lie somewhere in the mid-range in this continuum of severity.

For behavioral problems that are direct consequences of brain damage, Lezak (1988) argued that dysfunctional behaviours include: (i) impaired social perception and social awareness; (ii) impaired executive control, self-regulation, and adaptation of complex behaviour, of which the most obvious manifestations include difficulties with impulsivity, anger outbursts, or aggressiveness tendencies (Bond, 1983; Levin & Grossman, 1978; Luria, 1966, Walsh, 1978b, cited in Lezak, 1988); (iii) physical and emotional dependency; (iv) an inability to learn from experience, and (iv) specific emotional alterations.

If the gamut of direct consequences following traumatic brain injury appears overwhelming, the indirect consequences of brain damage are no less intimidating since
they involve responses to the experience of loss. As such, the indirect behavioral consequences of traumatic brain injury include: (i) anxiety, (ii) paranoia, and (iii) depression (Lezak, 1988).

A brain-injured individual's experience of himself/herself has unaccountably changed. Anxiety, accordingly, arises out of the awareness of an altered mental status, and gives rise to undue cautiousness, feelings of inadequacy, and confusion. In view of this awareness, it is not surprising that individuals' self-confidence, self-esteem, and self-perception change drastically as a result of trauma (Garski & Thomas, 1992; Johnson & Newton, 1987; Weaver, 1987). Paranoia constitutes another indirect consequence of traumatic brain injury. As Lezak, 1988, explained, "Perceptual inaccuracy, coupled with lack of insight, feelings of worthlessness (because of incompetencies), and fears of rejection (because of those incompetencies), create fertile ground for the development of paranoia" (p.120).

Lastly, depression may occur as an indirect consequence of head trauma. While presenting the family with emotional behaviour that is unsettling and difficult to deal with, depression also tends to feed on and exacerbate the individual's other emotional and social maladaptation. Left without clinical intervention, it may erode family members' self-esteem, and enhance their feelings of guilt and inadequacy because it is so resistant to their efforts to relieve it. Clearly, given the gamut of consequences of head trauma, both direct and indirect, it is vital that the appropriate counselling, educational, and emotional support systems be in place for both the brain-injured individual and family members.
Etiology/Pathobiology

In this section of the literature review, the causes of brain injury are discussed as are the various types of traumatic brain injury. Pathobiological research reveals that there are two types of traumatic brain injury: (i) missile or, (ii) non-missile (Povlishock & Valadka, cited in Finlayson & Garner, 1994). Penetrating missile injuries create localized, focal lesions that result in morbidity directly related to the primary site of injury. Examples of this type of injury include gunshot wounds. In such individuals, mortality is usually high; yet in those who survive, recovery is sometimes surprisingly good because of the highly focal nature of the primary insult (Povlishock & Valadka, cited in Finlayson & Garner, 1994).

Non-missile injury to the brain, by comparison, subjects the brain to shear and tensile forces that involve both local as well as diffuse brain abnormalities. Non-missile injuries include motor vehicle accidents, falls, sporting-related accidents, and assaults (Povlishock & Valadka, cited in Finlayson & Garner, 1994). With assaults or falls, it is allegedly typical to see more focal damage related to the area of primary contact. Additionally, with fracture of the cranial vault, there may be damage to the superficial epidural vessels and, particularly in the case of falls, a rupturing of the bridging vessels can occur.

Motor vehicle accidents, by contrast, cause much more complex and devastating brain injury. In such cases, due, in part, to the differential acceleration of the brain, both focal as well as diffusely localized damage can occur (Povlishock & Valadka, cited in Finlayson & Garner, 1994). Focal abnormality traditionally includes contusion and haematoma formation, while diffuse injuries involve diffuse axonal injury hypoxic/ischemic
change, diffuse brain swelling, and rarely diffuse petechial hemorrhage (Adams, Doyle, Ford, Graham, & McLennan, 1985). With most vehicular accidents, the brain sustains translational forces that move the brain in a sagittal plane in the cranial vault. This causes the frontal and temporal poles to move over the bony, rough cranial vault, with focal contusions occurring as the consequence of this movement (Povlishock & Valadka, cited in Finlayson & Garner, 1994). During motor vehicle accidents, the brain is also subjected to rotational/angular acceleration, which causes more diffuse central nervous system involvement. Rotational/angular forces of injury bring shear and tensile forces to bear on the brain, thereby damaging fibres and microvessels scattered throughout the brain parenchyma (Adams, Graham, Murray, & Scott, 1982). Hence, traumatic brain injury involves an avalanche of reactive change involving both structural and functional consequences in the brain parenchyma and its related vasculature (Povlishock & Valadka, cited in Finlayson & Garner, 1994). In the case of severe traumatic brain injury, neural and vascular dysfunction appear to be co-contributors to morbidity and mortality, and, as such, most of the contemporary clinical approaches are targeted to address these (Povlishock & Valadka, cited in Finlayson & Garner, 1994).

**Severity of Brain Injury**

Changes in the level of consciousness constitute the earliest sign of neurologic deterioration following brain injury (Rosenthal, Griffith, Bond, & Miller, 1983). The most consistent effect of diffuse brain damage, even when it is mild, is impairment of consciousness. As Jennett and Teasdale (1981) confirmed, the best indicator of the
severity of brain damage is the degree and duration of altered consciousness. Inconsistencies in the measurement of severity, however, represented obstacles for the progress of the epidemiological study of brain injury (Kraus et al., 1990). To facilitate the study of the epidemiology, treatment, and outcome of brain injury, it is important to define the type and severity of injury (Jennett, cited in Rosenthal et al., 1983.) Developed in 1974 by Teasdale and Jennett, the Glasgow Coma Scale (CGS) has gained increasing acceptance as a quantitative index of the severity of brain injury (Jennett & Teasdale, 1981).

The scale measures three elements of neurologic functioning: (i) degree of eye opening, (ii) motor, and (iii) verbal responses to standard stimuli (Glasgow Coma Scale in Rosenthal et al., 1983, p.16). Since the instrument measures the severity of injury, it can accurately reflect figures on the incidence and outcome of head trauma. Individuals who are admitted to the hospital with a Glasgow Coma Scale score of eight (8) or lower are generally defined as "severely" brain-injured. Those with a GCS score of nine (9) or greater are defined as "moderately" injured if they had a hospital stay of at least 48 hours, a GCS score below 13, an abnormal computed tomographic scan, or brain surgery. All other cases are termed "mild" (Kraus et al., 1990).

Consistent with Teasdale and Jennett's guidelines (1981), Cohadon, Richer, and Castel (1991) reported that brain injuries are generally classified in three groups according to the severity of the injury. Whereas "severe" injuries characterize brain injuries or coma of longer than six hours, "moderate" injuries are those referring to skull fractures without diagnosed brain injury or loss of consciousness between fifteen minutes and six hours.
"Mild" injuries, in the opinion of these researchers, consist of contusions without loss of consciousness, or a loss of consciousness for less than fifteen minutes.

**Limitations of Epidemiologic Research**

The epidemiological study of brain injury involves a numeric count of the number of brain injuries that occur in any given period, for a particular population, as well as the nature of the victims, and the causes of the injury (Jennett, cited in Rosenthal et al., 1983). Insights from the epidemiological study of brain injury are hampered by severe limitations in the quality and quantity of information available in the scientific literature (Kraus et al., 1990). One striking aspect of the existing epidemiologic literature has been the lack of a consistent definition of brain injury (Kraus et al., 1990; Snow, Macartney-Filgate, Schwartz, Klonoff, & Ridgley, 1988).

In addition to inconsistencies in the scope and definition of brain injury, there are variations and, indeed, apparent interchangeability, surrounding the usage of terms. For instance, some researchers speak of "brain injury," "brain damage," or "head injury," while others refer to "acquired brain injury," and still others designate the subject as "traumatic brain injury." The fact that explanations rarely follow, surrounding the differences in the use of the term, only seems to confound the issue further.

Other limitations that plague epidemiological brain injury research include differences in the procedures utilized for the identification of subjects. The use of different data sources (i.e., hospital admission and discharge records) and inconsistencies in the measurement of severity further contribute to limitations in epidemiological research.
(Kraus et al., 1990). Other research reports difficulties associated with an absence of common diagnostic criteria, rendering it difficult to compare the results of various studies (Snow et al., 1990). In other literature, limitations are based on the fact that injury data are self-reported and thus lack clinical confirmation. Alternatively, injury data do not adequately discriminate between self-treated or medically-treated injuries. Neither do such data adequately distinguish new injuries from previous ones (Frankowski, cited in Peterson & O'Shanick, 1986). Despite these various limitations, however, the potential magnitude of the health concern is substantial (Frankowski, cited in Peterson & O'Shanick, 1986), as our review of epidemiological research will indicate.

### Incidence and Prevalence

Incidence and prevalence are two common measures of the frequency of brain injury for a defined population (Frankowski, cited in Peterson & O'Shanick, 1986).

"Prevalence is the proportion of a defined population affected by brain injury at a specified point in time. The numerator of the proportion is all persons in a population affected by brain injury at that instant, regardless of whether the injury was incurred in the recent or distant past" (Frankowski, cited in Peterson & O'Shanick, 1986, p.155). "Incidence refers to new cases of brain injury, both fatal and nonfatal, occurring among previously unaffected individuals of a defined population" (Frankowski, cited in Peterson & O'Shanick, 1986, p.155).

The only published information available about the occurrence of brain injury for the population of the United States, prior to 1980, was that gathered by the National
Center for Health Statistics (NCHS) in its Health Interview Survey. During the period of 1970 to 1976, brain injuries accounted for 12% of 65 million injuries reported by the NCHS (Caveness, 1979). Whereas approximately four percent of the population of the United States annually reported some type of brain injury, one of four injuries were classified as "severe." As is frequently the case, however, the data are, in reality, under-represented. Since there are a certain number of incidences which remain unreported, this statistic represents a conservative estimate.

For the period 1970 to 1976, more than one million brain injuries per year were reported for the population of the United States (Caveness, 1979). Despite numerous limitations of the original NCHS data, the potential magnitude of the health concern of brain injuries was apparent, and this preliminary research initiative spurred numerous independent investigations. The surveys attempted to answer, for defined populations, who sustained head injuries, the type and severity of the head injuries, as well as when and where injuries occur, and why. These inquiries form the basis of the descriptive epidemiology of brain injury (Frankowski, cited in Peterson & O'Shanick, 1986).

The first specialized survey of the frequency and rates of head injury for the United States population was the National Head and Spinal Cord Injury Survey (Anderson, Kalsbeck, & Hartwell, 1980). The occurrence of brain injury was measured by enumeration of hospital admission and discharge records. For the United States population in 1974, the rate of hospitalization for incident brain injury was consistently estimated at 200 per 100,000 population (i.e., 20,000 serious brain injuries) (Anderson et al., 1980; Finlayson & Garner, 1994).
Of the 422,000 new hospitalized cases of brain injury reported in 1974 -- the frequency of existing cases of brain injury in the U.S. population for 1974, as judged by the number of re-hospitalizations for brain injury, was twice the rate of occurrence for new injuries. Otherwise stated, a total of 926,000 cases of brain injuries through 1970-74 still required hospital treatment and re-admission in 1974. For the total population in 1974, direct-care plus direct costs associated with brain injuries were $2.4 billion (Kalsbeck, McLaurin, Harris, & Miller, 1980). Though the range of severity of injuries was unknown, the national survey estimated that 75% of new injuries were concussions, 6% were cerebral lacerations or contusions, and 2% were haematomas.

If brain injury is taken as evident intracranial injury, skull fracture, or brain injury is accompanied with loss of consciousness or post-traumatic amnesia, then incidence rates for large U.S. population groups range from approximately 0.2-0.3% per year. Approximately 10% of the incident brain injuries are fatal (Frankowski, cited in Peterson & O'Shanick, 1986).

In Canada, by comparison to brain injury incidence in the United States, it has been estimated that there are between 20,000 and 30,000 serious brain injuries each year. In 1983, over 3,400 deaths were attributed to such injuries (Anderson et al., 1980). Although the exact economic costs of brain injury to Canadian society are unknown, statistics from the U.S give some idea of their potential magnitude. It was mentioned earlier that, in 1974, the total direct and indirect economic costs of brain injury in the U.S. were estimated at over $2.4 billion (Kalsbeck et al., 1980). If that figure is adjusted to reflect population differences between the two countries, then the equivalent costs to
Canadian society at that time would have been approximately $230 million (Snow et al., 1986). Ivan (1984) estimated that the economic cost of brain trauma to Canada is four billion dollars per year.

Two general demographic observations dominate population reports on the incidence of brain injury. Age and gender are pervasive demographic factors associated with the incidence of head injury: Males are at least twice as likely as females to sustain a brain injury (Frankowski, cited in Peterson & O'Shanick, 1986; Willer, Abosch, & Dahmer, 1990; Kraus et al., 1990). Brain injury is also markedly elevated among young adults and among the elderly, though male age-specific incidence is greater than female incidence throughout the entire lifespan. The most pronounced incidence is for males between the ages of 15-24, where the ratio of male to female incidence approaches 3.0 (Frankowski, cited in Peterson & O'Shanick, 1986). At age 70, male incidence increases rapidly.

Motor vehicle accidents are responsible for at least 50% of all brain injuries. Of 1,611 acute brain injuries due to transportation, nearly 2/3 were sustained by occupants of motor vehicles. Motorcycle accidents accounted for nearly 20%, followed by vehicle-pedestrian accidents (12%), and vehicle-bicyclist accidents (6%) (Kraus, Black, Hessol, Ley, Rokaw, Sullivan, Bowers, Knowlton, & Marshall, 1980).

Falls, on the other hand, account for approximately 20% to 30% of brain injury incidence. Assault explains 7% to 40% of all incidence of brain injury. Finally, recreation-related injuries reportedly cause 3%-14% of brain injuries (Frankowski, cited in Peterson & O'Shanick, 1986; Kraus et al., 1990). Interestingly, regardless of geographical location,
the Cohadon et al., 1991, study conducted in Bordeaux, France, reported consistently comparable data to those gathered in the United States and the United Kingdom.

As far as outcome data is concerned, among the group of severe brain injuries admitted to hospitals, the overall mortality is between 35% and 50%, with 2%-5% of individuals remaining in a persistent vegetative state (Cohadon et al., 1991). Despite numerous differences in the management of brain-injured individuals in various types of institutions and apparent medical progresses in the rescue systems and in intensive care medicine, these figures have allegedly been consistent over the last 10 years (Cohadon et al., 1991). The majority of brain injuries appear to be mild, but perhaps up to 30% are serious, life-threatening injuries posing significant sequelae to those who survive (Frankowski, cited in Peterson & O'Shanick, 1986). In terms of the consequences of severe brain trauma on daily life, 21% of individuals with minor brain injury and 24% of individuals with limited personality changes were, in fact, unable to manage a normal social life (Cohadon et al., 1991). Moreover, 43% of severely brain-injured individuals were still at home two years post-injury, and 12% were institutionalized. Although 31% of the severely brain-injured group was able to perform some type of work, they were incapable of independent living and were admitted to sheltered work places (Cohadon et al., 1991).

**Summary of Epidemiological Literature**

Accidents, homicide, and suicide are major cases of mortality and morbidity in the United States (Frankowski, cited in Peterson & O'Shanick, 1986). Each year, these three
causes of death claim nearly 160,000 lives (National Center for Health Statistics, 1980; 1982). Nearly 2/3 of all fatal injuries are caused by accidents, mostly motor vehicle accidents. The remaining are caused by homicide and suicide. Injury is therefore the leading cause of death for ages 1 through 45, the leading cause of years of productive life lost, a particular threat to the elderly, and the fifth cause of all hospital admissions in the United States (National Center for Health Statistics, 1982). Although trauma results in more years of lost life than cancer and heart disease combined, and probably many times the years of productivity, the funds spent on research for all trauma is only approximately 0.7% of that spent on cancer and heart disease (Trunkey, 1983).

Brain injuries constitute a substantial but imprecisely known proportion of all injury morbidity in the United States (Frankowski, cited in Peterson & O'Shanick, 1986). Apart from difficulties estimating the total number of incidents due to lack of universal definition, there is under-representation in the reporting of incidents (unless complications arise). At other times, incidents are only reported where injuries lead to either death, hospital admission, or attendance at accident sites. With these limitations in mind, studies of brain injury in the United States can be interpreted to indicate that the approximate incidence of fatal brain injury and non-fatal hospital-treated brain injury varies from 0.2 to 0.3% per year among large and diverse U.S. populations (Frankowski, cited in Peterson & O'Shanick, 1986).

Finally, incidence patterns place the young and the elderly at particular risk. Males sustain brain injury twice as often as females, reflecting gender differences in the kind, degree, and exposure of males to the hazards of brain injury. The alarming
epidemiological data on brain injury have not passed attention. One of the national objectives of the United States has been to attempt to reduce morbidity and mortality from traumatic brain injuries (Davis, Schletty, Ing, & Weisman, 1984). Prevention programmes and education relating to the use of well-designed and properly worn helmets and particularly the use of seatbelts, remain our best defence for injury prevention (Kraus et al., 1990).

**Impact of Traumatic Brain Injury upon the Family System**

**Family Members as a Treatment Group in Their Own Right**

The purpose of this section of the literature review was to focus upon an introduction into family issues, determine that brain injury is indeed a "family affair" (Lezak, 1988, p.111), and review the impact of traumatic brain injury upon the family system.

The criticisms that may be directed at this body of literature relate mainly to the gaps in the research. Firstly, though the medical standpoint of the issue under investigation is well represented in the literature, the psychological vantage point is considerably less remarkable. Secondly, in comparison with the more widely documented effects upon brain-injured individuals, little has been written about the impact of traumatic brain injury upon the family system. If family members are mentioned in this particular research at all, it is in the way they can be used as an instrument towards the successful rehabilitation of their loved one, not as a treatment group in their own right (Canboy, Barth, & Boll, 1986). The enlistment of family as a tool for structuring and maximizing
the survivor's environment undoubtedly represents worthy clinical and research goals; however, there is a need for family members to be recognized not only as service providers, but as a worthy treatment group in their own right.

**Brain Damage as a Family Affair**

A body of research conducted by Lezak (1986; 1988), Davis (1988), DePompei et al., (1987), Schwentor and Brown (1989) concurred that "brain damage is a family affair" (Lezak, 1988, p.111), and, accordingly, perceived family members as victims. For all of the brain-injured individual's deficits and limitations documented in our epidemiological review of the literature, Lezak (1988) described their deleterious effects upon family members. As mentioned earlier, one of the corollaries of brain injury is impaired social perception and social awareness: An individual who has sustained brain injury generally displays a childlike egocentricity. Lezak (1988) argued that individuals whose egocentricity is a product of brain damage may be compromised in their capacity to be aware of social signals or to interpret them accurately. This difficulty has many implications for the family. For one thing, people who lack the capacity to be socially sensitive and considerate can place a constant burden of demands on loved ones. Furthermore, family and friends may abandon self-centred individuals, regardless of the origin of their egocentrism. The self-centredness may also show itself as an incessant expectation for assistance, or demand for attention, which is unabated regardless of effort. For all of these reasons, a loved one's egocentricity places onerous demands upon family members (Lezak, 1988).
Impaired executive control may take the form of over-indulgence, which may result in worry for family members (Lezak, 1988). Alternatively, control problems may disguise themselves as restlessness, agitation, and impatience. Such dysfunctional behaviours are likely to adversely affect family functioning since requests to family members are expressed as demands. Additionally, impatience feeds the brain-injured individual's frustrations, and invites the likelihood of irritability and temper outbursts. At the same time as the brain-injured family member experiences difficulties with self-control, his/her rigidity and lack of flexibility threatens the very existence and well-being of the family unit.

Dependency, like all other behavioral alterations, further impacts upon the nature of family relationships and family life (Lezak, 1988). When the loved one's needs exceed the family's capacity to provide adequate care or assistance, guilt ensues. According to Lezak (1988), however, it is the individual's emotional dependency that is typically experienced as much more burdensome than physical dependency. Brain-injured individuals develop reactive attitudes and habits of emotional dependency that are beyond their realistic needs. Lezak argued that the danger is that such dependency fosters vicious circles which tend to sustain and strengthen the individual's feelings of inadequacy, loss of control and authority, and anger. Other forms of dependency involve reliance upon family members, to help plan and take charge of their loved one's life. This structure-dependency (Lezak, 1988) means that family members feel the necessity of externally guiding, supporting, and coaching their loved one through daily living activities. Due to the individuals' reduced ability -- and in the worst case scenario, complete inability -- to
organize, initiate, or plan for themselves, it becomes incumbent upon the family to develop a structured setting while at the same time being encumbered by the monotony and rigidity of such a setting.

An inability to learn from experience represents another direct consequence of traumatic brain injury, which poses other difficulties for families of the brain-injured. The implication of reduced learning ability is that the family must treat each situation as if it were a newly encountered one (Lezak, 1988). This requires constant vigilance and energy on the family's part. Additionally, family members may experience tremendous stress in witnessing a repetitious, albeit erroneous, response pattern, which remains impervious to encouragement, coaching, or support.

Families may further find it difficult to comprehend, much less tolerate, specific emotional changes such as apathy, silliness, heightened reactivity, and irritability (Lezak, 1988). Emotional alterations in behaviour are especially difficult for family members in view of their erroneous assumption that their loved one could control himself/herself if he/she would simply attend to his/her maladaptive behaviour and attempt to exercise control over it. As discussed, however, attending behaviour and self-control are at the heart of a brain-injured individual's limitations.

In Lezak's (1988) discussion of behavioral disturbances, she cautioned that it is important to realize that these difficulties can be quite subtle. This subtlety may make it arduous for unprepared family members to appreciate the unsettling and irritating nature of their loved one's behaviour. Moreover, even persons who have undergone extensive personality alterations can exercise some control over their aberrant behaviour, at least for
short periods of time and under well-structured environments (Lezak, 1988). Hence, the chameleon-like character presented by some individuals creates additional difficulties for family.

Difficulties are compounded by the fact that all looks well to "outsiders." This appearance of wellness, however, runs counter to the fact that, often, families of brain-injured individuals typically experience at least some social problems involving social isolation, loss of emotional supports, restricted independence, and financial strain, as well as psychological experiences of bewilderment, frustration, guilt, and depression (Lezak, 1988).

Other literature similarly acknowledges that the traumatic brain injury of a loved one is a major family stressor since it places onerous demands and challenges upon family members (Perlesz et al., 1992; Pessar et al., 1993). Indeed, still other researchers corroborate this finding: In Anderson-Parente, DeCesare, and Parente's (1990) survey of seven (7) married couples -- in which one person had sustained a traumatic brain injury following marriage -- less than one third of those who were married remained in their relationships. None of the family members were employed, while six out of seven members had experienced severe financial hardship, and nearly all had complained of a diminished social life.

Similarly, Hartman's (1987) body of evidence suggested that traumatic brain injury of a loved one places onerous demands and challenges upon family members. Hartman (1987) investigated the effect of severe head injury upon the family by studying seven males who experienced behavioral changes following injury. Likewise, Bragg, Klockars,
and Berninger (1992) compared families with and without a head-injured adolescent in regard to measures of perceived family functioning, projected autonomy, and maladaptive behaviour. Instruments such as the Vineyard Adaptive Behaviour Scales were administered to parents, adolescents, and their siblings. Results indicated that families with a brain-injured family member had perceived significantly poorer family functioning, and the traumatically brain-injured (TBI) adolescents showed significantly more maladaptive behaviour than the control group. Hence, the literature acknowledges that family changes incurred as a result of brain injury can be severe, functionally significant, and prolonged.

**Family Adaptation to Traumatic Brain Injury**

Having established that brain injury is a family phenomenon, and having examined the evidence in the literature for its deleterious effects upon the family system, the following section reviews the adaptation literature as it relates to the brain-injured family. Although much has been written about the family's psychological adaptation to the traumatic brain injury of a family member, there is a dearth of existing data in the area of family outcome. Very few studies have characterized family outcome over time (Stiles Camplair, Kreutzer, & Doherty, cited in Kreutzer & Wehman, 1990). More specifically, most research investigating emotional distress has addressed only the first year post-injury; that is, investigators have typically reported on family reactions at certain time intervals (i.e., 3, 6, and 12 months post-injury). Time post-injury, however, is critical because of the implied relationship to various processes, including the head-injured person's recovery,
a process for determining the feasibility and practicality of each project. The projects are then prioritized based on their potential impact and alignment with the organization's strategic goals. This prioritization process helps ensure that resources are allocated effectively to the most promising projects.

Implementation:

Once the projects are prioritized, a detailed implementation plan is developed for each project. This includes defining the scope, timelines, budget, and responsibilities for each project. The plan is then communicated to all stakeholders, and project teams are established to manage the execution of each project.

Monitoring and Evaluation:

Throughout the project development and implementation phases, the projects are monitored closely to assess their progress against the planned timelines and budgets. Regular updates are provided to stakeholders, and adjustments are made as necessary to ensure that the projects remain on track. Once the projects are completed, they are evaluated to assess their success in achieving the desired outcomes and to identify any areas for improvement in future projects.
his/her resumption of responsibilities, and the family's adjustment process (Stiles Camplair, et al., 1990). Recognizing the fact that most studies focus upon the acute and rehabilitation phases (Rivara, Fay, Jaffe, Polissar, Shurtleff, & Martin, 1992; McLaughlin & Carey, 1993) the focus of this research study is on brain-injured individuals and families who are 18 months to four years post-trauma, and whose onset of injury and time since discharge from the rehabilitative facility is at least six months (and ideally beyond one year) prior to the family's participation in the study. The uniqueness of the sample characteristics, therefore, contributes to the narrowing of knowledge gaps in this particular body of literature, thus acknowledging that the transition between the post-acute to community re-integration phase represents the most serious threat to satisfaction with rehabilitative service.

Secondly, one finds that research addressing the prevalence and nature of distress and impaired functioning among families of brain-injured individuals in the United States is lacking (Stiles Camplair, et al., 1990). Information available from abroad may be of limited utility, given significant differences between these populations and those of the U.S. In addition, researchers must employ validated assessment instruments, carefully describe their samples, and incorporate multiple sources of information in order to adequately characterize family reactions (Stiles Camplair, et al., 1990). Attention to the these methodological limitations in this research study will likely improve our understanding of family responses to brain injury.

In addition to criticisms relating to gaps in the literature and methodological limitations, this particular body of information appears to operate within diverse
conceptual frameworks. For example, I have often found that researchers mean different things when they speak about "adaptation." I believe, therefore, that there is a need for greater conceptual clarity in this particular body of literature. Another related criticism is this literature appears to be hazy on the conceptual differences between adaptation, adjustment, family functioning, and coping; instead, these terms appear to be utilized interchangeably. If concepts are "fuzzy," then the possibility of a cohesive, unified framework becomes remote.

In reviewing this literature, for example, one finds that some researchers describe a family's psychological adaptation in terms of a typology. Research conducted by Lezak (1986) and Spanbock (1987), revealed a typology of familial reaction patterns characterized by developmental stage theory. Lezak (1986) argued that family members undergo a series of stages in their adaptation to the traumatic brain injury of a loved one, namely: pleasure ("My loved one is alive!"), bewilderment/anxiety, guilt, depression, despair, mourning, reorganization and emotional disengagement.

Spanbock (1987) concurred with the stage approach as a description of psychological adaptation, but qualified the adaptation somewhat differently as: shock, elation, realism, crisis, mourning and redefining. He argued that psychological intervention can help families negotiate these stages by helping them to understand the nature and effect of the injury, facilitating more realistic expectations, and helping them work through the conflicts and pain engendered by injury. Though these developmental models were proposed to conceptualize the family's adaptation to a brain-injured member, Rape, Bush, and Slavid (1992) have criticized them, indicating that hypotheses about
stages have not been subjected to empirical investigation.

Other bodies of research view families' adaptation in terms of the changes in family roles and interaction patterns. Lezak (1988) believed the changes in family members' roles and interaction patterns vary according to the nature and severity of problems experienced by family members and from family to family. The changes vary depending upon such factors as pre-morbid cohesiveness, family attitudes about illness and responsibility, and financial and social supports. The role changes allegedly differ among family members as there is great variance in various individual members' acceptance and adaptation to disability.

According to Lezak (1988), almost any enduring behavioral alteration creates difficulties for a family accustomed to a person they knew and loved. Lezak (1988) believed that family roles, interaction patterns, and dynamics must of necessity change in order to accommodate the changed status of their loved one. The need for "re-scripting" family roles has been confirmed by Davis (1988), who argued that life takes on a radical and permanent change the moment one hears the news.

Likewise, Acorn and Roberts (1992) corroborated this view of psychological adaptation. In their examination of the impact of brain injury upon spouses, Acorn and Roberts (1992) analyzed data through the use of content analysis. Emerging themes were: role changes, emotional impact of the injury, hope, and need for support. She found that spouses of brain-injured individuals often need considerable support because of the myriad of role transitions and role changes they experience. The implications for practice and research include the need for support groups, the importance of fostering hope, and the
need for education of health care professionals.

Similarly, DePompei, and Zarski (1989) described general functional and dysfunctional family responses that may be anticipated when a family member experiences head trauma. These researchers alluded to the need for role alteration or reformulation of family rules to curtail stress overload and dysfunction. In their study, DePompei and Zarski (1989) outlined three family cognitive-communicative disorders, and emphasized the role of educational counselling in promoting adaptive skills. They believed family counselling may address the emotional trauma of the event, while family therapy may prove helpful in understanding the family's systemic functioning and conflict.

More explanatory bodies of research describe families' psychological adaptation in terms of family stressors. Baker (1990) reviewed the family's adaptation to the head trauma of a loved one using a medical stressors model. Significant correlations were found between: the presence of rules in the family that permit emotional expression and depression; assistance the parents felt was available and trust; the actual number of people available for assistance outside the nuclear family and illness anxiety; and role flexibility and depression.

**Family Adjustment to Traumatic Brain Injury, and Coping Literature**

Peters, Stambrook, Moore, Zubek, Dubo, and Blumenschein (1992) documented that clinicians have long recognized the adjustment difficulties posed in marriages of trauma victims; yet, there is little research documentation for this observation. The marital relationships of a moderate and severe brain-injured group and a spinal cord injury group
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were assessed through spouses' self-reports in interviews and through standardized questionnaires. In the post-injury marital relationship, the "severe" head-injured group was significantly lower than the "moderate" and spinal group on standardized and validated scales assessing affectional expression, dyadic satisfaction, dyadic cohesion, and total dyadic adjustment. Results of the Peters et al. (1992) research revealed that the adjustment difficulties may be more severe for spouses of the severely brain-injured as compared with those of the moderately brain-injured or spinal cord injured.

As far as the coping literature is concerned, at least vis-a-vis families and brain injury, one finds that, in the 1980s, there was a paucity of research in this area. At that time, it appears that very little, if any, research documented the coping strategies in use by family members. Nor did researchers establish the relationships between coping behaviours, healthy family adjustment, and adaptation to brain trauma. In the 1990s, however, there appears to be an increasing body of literature on coping strategies and implications for family adaptation.

Frank, Haut, Smick, Haut, and Chaney (1990) believed that cognitive deficits associated with closed head injury (CHI) have been well studied. Less attention has been directed to the emotional consequences of CHI and subsequent attempts to cope with major life events. Closed head injury constitutes one type of catastrophic head injury; yet, few studies have examined the coping strategies used by individuals following injury, or the effects of CHI on family functioning that may mediate coping. In a preliminary investigation, 40 patients with closed head injury were compared with 17 neurological intact controls. The closed head injured group was divided into two sub-groups according
to time since injury. It was found that closed head injury patients utilized information seeking as their most dominant coping strategy, regardless of time since injury. Moreover, patients with closed head injury had higher family cohesion scores than control subjects.

Willer, Allen, Liss, and Zicht (1991) addressed the problems and coping strategies of 20 married men and 91 married women with traumatic brain injury and their spouses. A structured, small group discussion process was used to elicit a prioritized list of problems and a similar list of coping strategies. Martin (1988) examined the potential impact of traumatic brain injury to a child on the family, and the complex array of factors that appear to be related to effective family coping and adaptation. The sources of family stress were found to be related to the sudden and dramatic changes in the child's cognitive abilities and personality, ambiguity about recovery, the increased dependency, and longer-term care needs. Other stressors included the lack of financial resources, respite care, and appropriate community resources and educational programs.

There are a number of additional studies which deal with the use of coping strategies and their implications for family adaptation. Orsillo, McCaffrey, and Fisher (1993) investigated the stress associated with having a head-injured sibling by examining the problem-solving abilities, coping styles, family functioning, attributional styles, beliefs, attitudes and levels of psychological symptomatology of 13 siblings of severely head-injured individuals. Subjects reportedly showed significant levels of psychological distress on the Brief Symptom Inventory, endorsed significantly more distorted, idiosyncratic beliefs on the Dysfunctional Attitude Scale, and scored significantly poorer on problem-solving tests. They displayed emotional coping patterns by endorsing the use of strategies
such as wishful thinking, avoidance, and self-blame to cope with their problems.

Likewise, Moore, Stambrook, Peters, and Lubusko (1991) investigated the coping strategies used by families of 13 severe, 22 moderate, and 11 mild head-injured male patients, and the relationship of these strategies to marital adjustment. Families who demonstrated high-use of coping strategies reported higher dyadic adjustment, while low-use families reported higher sexual intimacy. The amount and pattern of coping strategy use, as well as age, appear to be important factors in accounting for the relationship between coping strategies and marital adjustment.

Willer, Allen, Durnan, and Ferry (1990) conducted structured small group discussions with 13 young men with TBI, their mothers, and siblings to determine the problems they encountered and the coping strategies they found most useful. Brain injured subjects experienced problems with peer relations, autonomy, and success at school. Problems addressed by mothers related more to the service system and its accessibility, and siblings listed family stress as most problematic. Brain-injured subjects coped through personal responsibility for progress, while mothers identified acceptance of their sons as their primary means of coping. Siblings tended to use suppression of frustrations as their principal means of coping.

Though researchers have examined the issue of coping, they have not consistently drawn implications for clinicians or helping professionals. Additional research should therefore review in greater detail the strategies and interventions which will assist clinical practitioners in their practice and research of rehabilitative counselling with families of the brain-injured.
Interventions Literature

Finally, this section informs researcher and readers alike as to the types of interventions available for use by clinicians in their quest to assist families of the brain-injured. There seems to be relatively little in the literature that speaks directly on the issue of interventions for families of brain-injured individuals, in comparison to individual brain-injury survivors. Most of the intervention literature appears to be directed towards the brain-injured client. For example, Carberry and Burd (1986) discussed individual psychotherapy with the brain-injured adult. These researchers recommended that therapy with the brain-injured needs to be direct, structured, and innovative. Additionally, psychotherapy must focus on cognitive deficits and retraining; it must work within the context of the life problem that brings the client into therapy.

Barry and O'Leary (1989) examined the role of the psychologist on a traumatic brain injury rehabilitation team. They believed that the role requires proficiency in neuropsychological assessment, behaviour management, understanding of family systems, psychology of disability, cognitive rehabilitation, and short-term psychotherapy.

Within the narrower body of literature relating to strategies for intervention with families of the brain-injured (Kreutzer, Zasler, Stiles Camplair, & Leininger, 1990; Rosenthal, 1984), Jackson and Haverkamp's research (1991) revealed that the burden on family members apparently does not improve, and may even grow worse over time. Consequently, the necessity for family counselling intervention is indicated.

Likewise, Florian and Katz (1991) concurred that family members often require intensive intervention services and psychological support, not just as caregivers, but also
as a treatment target population in their own right. Intensive intervention services should begin with a comprehensive evaluation and assessment of the status and needs of the family and each family member. Cognitive, emotional, and social support can be provided with individual and group counselling, emotional counselling, and family therapy.

Additionally, Hartlage (1988) believed that psychotherapists increasingly are being called on to provide psychotherapeutic support not only to victims, but also to their spouses and other family members. He suggested that psychotherapists in private practice who become aware of these emerging issues will be in a unique position to provide relevant services to this burgeoning population.

Still, other studies discuss the use of interventions in assisting families. Jarman and Stone (1989) explored the use of a family support group in assisting family members to cope with brain trauma. Reported benefits included support, a decrease in social isolation, problem-solving opportunities, and the chance to focus on the family's own needs.

Lauer-Listhaus (1991) described a program of psycho-educational group therapy developed to assist families of brain-injured adults in addressing judgement issues associated with changed roles and responsibilities. Topics centred around adjustment issues for the brain-injured, medical complications of head trauma, psychiatric problems following brain injury, social services and financial benefits available, communication strategies with language impaired head-injured adults, neuropsychological testing, vocational opportunities, and work re-entry. Group leaders found a structured format and the presence of supportive professionals to be critical in assisting families.
Schroeder (1993) articulated her belief that health care professionals can help by providing information, encouraging a discussion of feelings, and helping clients develop a network of peers to facilitate healthy adjustment. Of all interventions that professionals use with families, providing information about brain injury, rehabilitation, recovery, and management is probably the most vital. Yet, lack of information is often cited by families as one major failure of the medical system (Caplan, 1993).

Other research asserted that clinical interventions should focus upon educational and family counselling to support the family through the emotional trauma, to assist them in understanding the communicative impairment and its potential consequences, and to provide specific information about deficits and how they may affect life at home (DePomPei & Zarski, 1989). According to Sachs (1985), it is the professional's responsibility to help both the individual and family to regain meaning and purpose. Professionals need to help the family to reinterpret its experience in terms of growth and personal development. Perlesz et al. (1992) suggested family therapists might: (i) provide educational information about brain damage and its effects; (ii) arrange family support groups; (iii) be the family's advocate in the context of complex legal and financial bureaucracies; (iv) undertake marital, sexual, or family therapy; (iv) know where family members are in their negotiation of the tasks of grieving, restructuring, identity reformation, and achieving a sense of growth after head injury.

Finally, Zarski, West, DePompe, and Hall (1988) outlined for the mental health practitioner the family stressors commonly experienced during the process of adjusting to chronic illness. They presented a family systems model for understanding the impact of
chronic illness on family functioning and present several family-focused interventions relating to reducing stress involved in the chronic illness adjustment process.

**Summary of the Impact of TBI upon the Family System Literature**

The literature reviewed has addressed the impact of traumatic brain injury upon the family system. The purpose of this section was to focus upon an introduction into family issues, determine that brain injury affects the entire family unit, and review the impact of traumatic brain injury upon the family system. Although the medical standpoint of the issue under investigation is well represented in the literature, the psychological vantage point is considerably less remarkable. Given the scope of the deleterious effects of brain injury upon the family system, it is vital that researchers, clinicians, and educators evaluate family needs on an ongoing basis, and expand upon the body of research pertaining to rehabilitation counselling psychology. Practitioners must, moreover, draw applications from the clinical counselling psychology knowledge-base to the TBI family population directly. It is vital that rehabilitation counselling psychology further expand upon this particular knowledge-base if it is to effectively assist professionals with clinical practice.

Secondly, there has been relatively little written about the impact of traumatic brain injury upon the family system in comparison with the more widely documented effects upon brain-injured individuals. Currently, as psychotherapeutic interventions research focuses on the brain-injured individual, there is a need to build upon this literature for family members. What is needed, in this respect, is a theoretical multi-dimensional
null
model which applies various family therapy approaches with family members of the TBI population directly.

Thirdly, although much has been written about the family's psychological adaptation to the traumatic brain injury of a family member, there is a dearth of existing data in the area of family outcome. Since very few studies investigating emotional distress have characterized family outcome over time (Stiles Camplair, et al., 1990), there is a need to research family reactions beyond 12 months post-injury. Additionally, since most studies focus upon the acute and rehabilitation phases, there is a need to investigate emotional distress at the community re-integration phase of the rehabilitation process, thus acknowledging that the transition between the post-acute to community re-integration phase represents the most serious threat to satisfaction with rehabilitative service.

In addition to the more serious criticisms relating to gaps in the literature and methodological limitations, this particular body of literature appears to operate within diverse conceptual frameworks. The need for greater conceptual clarity between concepts like adaptation, adjustment, family functioning, and coping, is of paramount importance if the possibility of a cohesive, unified framework is to become a reality.

Fourthly, with respect to the coping literature -- although the research has examined the issue of coping, it has not examined the specific mechanisms utilized to facilitate adjustment. Finally, in regards to the literature on interventions, most of the literature reviewed appeared to be directed primarily towards the brain-injured client. Accordingly, there seems to be relatively little which speaks directly on the issue of
interventions for families of the brain-injured. Hence, additional research should build upon the narrow body of literature relating to strategies and interventions with families of the brain-injured for the purpose of assisting clinical practitioners in their practice and research of rehabilitative counselling with families of the brain-injured. Moreover, the scarcity of resources in the traumatic brain injury and family literature, and the tremendous challenges encountered in procuring professional journals in rehabilitation psychology, indicate that further research should attempt to apply counselling and psychotherapeutic practices to the families of brain-injured population. Based upon these preliminary research initiatives, it appears that further research is needed to expand upon the narrow and limited information base which counselling psychology offers to TBI families and rehabilitative practitioners alike.

Identification of the Needs of Families of the Brain-injured

Family Needs

In the third section of the literature review, the needs of families of the brain-injured are discussed, followed by a brief discussion of the concept of needs assessment. The following body of literature qualifies the nature of family needs following traumatic brain injury to a loved one, and supports the need for service to this target population.

In Campbell's (1988) examination of the needs of family members following brain injury, she found that priority needs centred upon the need for information and psychosocial support. The majority of Campbell's respondents stated that support groups generally satisfied their educational needs relating to brain injury as well as needs for
financial, and community resources.

Similarly, wives of brain-injured individuals often need considerable support due to the myriad of role transitions and role changes they experience (Acorn & Roberts, 1992). In Acorn and Robert's study (1992), participants consisted of 12 women caring for their brain-injured spouse. A questionnaire was adapted from Campbell's original instrument, which was developed from information gathered in a literature review of the effects of severe head injury on relatives. Respondents were asked to identify which of the items were important to them, and whether or not attendance at a support group was helpful to them in meeting the identified needs. Content analysis was used to analyze data. By sorting participants' responses into broad themes and then coding data into smaller categories, themes of role changes, emotional impact of the injury, hope, and need for support emerged. Participants felt that they needed to learn about their newly acquired caregiver role. In discussing the theme of emotional impact of the injury upon themselves as wives, they perceived that health care professionals' lack of expertise contributed to their sense of emotional burden. Participants additionally perceived communication problems between professionals and family members as emotionally taxing. Finally, participants reported the need for professionals to foster hope and facilitate meaningful adaptation to traumatic event.

Bragg, Klockars, and Berninger (1992) further described the family's psychological adaptation to brain trauma by identifying family stressors or needs of informal caregivers of brain-injured adults. Questionnaires were administered to 84 caregivers of brain-injured adults. Of the 110 needs identified by the subjects, 37 were categorized as intrapersonal...
stressors; 24 were categorized as interpersonal stressors; and 49 were categorized as extrapersonal stressors. Lack of time for self and time for social activities were the most prevalent intrapersonal stressors, while the need for support from family, friends, and health professionals constituted the most prevalent interpersonal stressors. Finally, the need for respite care, financial support for physical care, and day care programs that addressed the physical needs of brain-injured individuals represented extrapersonal stressors.

Mauss-Clum and Ryan (1981) investigated needs for professional help at the time of injury for a sample of wives and mothers of adults with central nervous system dysfunction. They administered a needs questionnaire developed by Molter (1979), for use with families with critically ill individuals. During their family members' initial hospitalization, families reported that the following needs were most important: (i) the need for a clear and kind explanation of their injured family member's condition and treatment; (ii) discussion of realistic expectations; and (iii) emotional support (Stiles Camplair et al., 1990). During the acute care phase, needs for financial and counselling were rated as least important.

Mathis's (1984) study, comparing families' needs of critically-ill patients with those of the brain-injured, reported the need for information pertaining to the injured individuals' status, and reassurance about the quality of medical care as most important. Additionally, the need to feel hope and to have questions answered honestly were considered to be very important for both groups.
Finally, Ostby, Sakata, and Leung (1988) administered a needs assessment questionnaire to 58 relatives or brain-injured individuals who had received acute care in either the hospital and/or rehabilitation services. Respondents were divided according to the rehabilitation services they had received and the level of severity of initial injuries. Common to all groups was the need for training the family on how to deal with the brain-injured individual. Most subjects reported a need for: family education; job training, and work programs; social and recreational services; and, financial assistance. In two of the four groups, most people indicated a need for additional educational materials, counselling, and assistance with the injured individuals' transition between home and work.

**Needs Assessment**

The work of Hermansen Williams (1990) substantiated the need to create mechanisms to regularly assess and evaluate the degree to which the activities of support groups meets the needs of its members. Ongoing research is necessary to determine the needs of families of the brain-injured in order to cost-effectively utilize the resources of health care professionals in provision of health care (Engli & Kirsivali-Farmer, 1993).

**Summary of Family Needs Literature**

This body of literature qualified the nature of family needs following traumatic brain injury to a loved one, and supported the need for service to this target population. Several criticisms may be launched against literature pertaining to the needs of families of the brain-injured. For one thing, only limited information is available on family needs
Him it.
following head injury (Stiles Camplair et al., 1990). For another, few studies have addressed family needs outside of the acute medical phase of rehabilitation. This research study, therefore, represents a pioneering initiative to investigate family needs in relation to the community integration phase of the rehabilitation process. Moreover, unlike its predecessors that investigated family needs, this is the first research study that examines family needs within the specific context of service delivery and programming initiatives. Its uniqueness lies in the correlation of family needs and services, on the one hand, and family needs and interventions rendered, on the other. Family perceptions of needs in this study are considered to be reflective of caregivers' satisfaction with rehabilitative treatment and care.

The review of the literature of needs assessment has ascertained the need to create mechanisms to regularly assess and evaluate the degree to which treatment interventions meet the needs of its members. Ongoing research is necessary to determine the needs of families of the brain-injured in order to cost-effectively utilize the resources of health care professionals in provision of health care.

Rehabilitation Counselling of Families of the Brain-injured

Introduction to the Concept of Rehabilitation

In this fourth part of the literature review, the concept of rehabilitation is introduced, as are the theoretical underpinnings of rehabilitation counselling practice. Following an identification of the types of services available to families of the brain-injured, the section concludes with a discussion of family treatment issues, and an
overview of interventions intended to enhance family adaptation to traumatic brain injury.

Rehabilitation is defined as the development of the person to the fullest physical, psychological, social, vocational, avocational, and educational potential consistent with his or her physiological or anatomical impairment and environmental limitations (Whyte & Rosenthal, 1988). The goal of rehabilitation is to reduce handicap by optimizing an individual's functioning. This optimization of functioning is fostered either through the enhancement of the individual's skill repertoire or the modification of the environment in which he/she must function (Finlayson & Garner, 1994).

Traditionally, professional attention and available resources have been directed to trauma support systems and early medical management in order to literally save the life of the brain-injured (Finlayson & Garner, 1994). However, once the injured individual has "healed" (i.e., by medical standards), there are fewer resources available to assist him/her with the successful reintegration into the community. As Rempel (1992) argued, the ability to "get a life" is significantly limited, and the brain-injured individual experiences post-coma abandonment.

Finlayson and Garner (1994) have found it helpful to conceptualize rehabilitation in the context of the classification of the consequences of disease proposed by the World Health Organization (WHO, 1980). The consequences of disorder or disease are viewed on three levels: (i) impairment, (ii) disability, and (iii) handicap. Accordingly, an impairment is "any loss or abnormality of psychological, physiological, or anatomical structure or function" (WHO, 1980, p.27). Disability, on the other hand, represents "any restriction or lack (resulting from impairment ) of ability to perform an activity in the
manner or within the range considered normal for a human being" (WHO, 1980, p.28).

In contrast, handicap is defined as "a disadvantage, for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, gender, and social and culture factors) for that individual" (WHO, 1980, p.29). Handicap is further conceptualized by The World Health Organization according to seven categories: orientation, physical independence, mobility, occupation, social integration, economic self-sufficiency, and other.

The common thread that weaves between all three consequences of disorder is an impediment, which interferes with one's ability and means to sustain life, one's capacity to love oneself and others, and one's opportunity to participate in purposeful, productive, and pleasurable activities (WHO, cited in Finlayson & Garner, 1994). Since the ultimate test of rehabilitation success is the functioning of individuals with acquired brain injury within the community, maintaining an appropriate balance between the physical/medical, on the one hand, and community reintegration, on the other, is crucial, and represents the major challenge facing rehabilitation professionals.

**Rehabilitation Service**

The literature review relating to rehabilitation service informs both researcher and readers about the types of services available to families of the brain-injured. Additionally, it addresses family treatment issues, and provides an overview of interventions intended to enhance family adaptation to traumatic brain injury.
Rosenthal, cited in Edelstein and Couture (1984), argued that it is imperative that health care professionals anticipate family distress and establish the appropriate mechanisms for providing family support prior to hospital discharge. The diagnostic process by which appropriate intervention techniques are selected and family intervention is made, consists of three major components: (i) analysis of pre-morbid history of injured individual and family -- such analysis is particularly important in view of the relationship between pre-morbid history and post-morbid adjustment; (ii) identification of the severity and potential duration of cognitive and physical deficits of the injured individual; and (iii) understanding "signals" from the family that would appear to reflect a need for intervention. Such signals may take the form of anxiety or fear about prognosis, confusion and helplessness concerning observed behavioural problems, or changes in role relationships that likely create disruptions in family functioning (Rosenthal, cited in Edelstein & Couture, 1984).

Kreutzer, Zasler, Stiles Camplair, and Leiningen, cited in Kreutzer and Wehman (1990) argued that the goals of family intervention strategies following brain injury are to improve the emotional well-being of individual family members and the functioning of the family unit. Kreutzer et al., cited in Kreutzer and Wehman (1990) described seven approaches to community intervention intended to benefit families of individuals with traumatic brain injury including family education, support groups, networking, advocacy, family therapy, marital therapy, and sexual counselling.

Family education focuses on providing family members with general information about traumatic brain injury and specific information about the injured individual. Such
education also includes available types of rehabilitation therapies, support, and advocacy, and the costs of available treatments (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Oddy, Humphrey, and Uttley (1978) reported that families expressed dissatisfaction with the communication between themselves and medical staff. The most frequent complaint was the need for greater information regarding the extent of brain injury and the state of recovery, as well as the lack of widely available written materials. The importance of education cannot be overstated: Patient-family education programs are designed to provide basic information about the nature of brain injury and its consequences, and to help families gain a greater understanding and acceptance of the disability and the rehabilitation process (Rosenthal, cited in Edelstein & Couture, 1984). If access to library resources is vital, it is especially important that educational material for families be stated in clear, easily understood language so as to alleviate, rather than exacerbate, a family's sense of feeling overwhelmed (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Similarly, if the educational material is selected on the basis of the family's specific needs, the likelihood of feelings of distrust, confusion, and lack of confidence in professionals is lessened. Other helpful resources include educational videotape and audiotape materials available through organizations such as The National Head Injury Foundation or Rehabilitation Research and Training Center on Traumatic Brain Injury (Kreutzer et al., cited in Kreutzer & Wehman, 1990). In addition to the aforementioned, another vehicle of family education is rehabilitation team meetings, which encourage the family to participate and ask questions. Finally, individual professionals are encouraged to schedule regular meetings that include family members to provide feedback regarding progress (Kreutzer et
Family support groups represent another type of structured approach to family intervention. The notion of peer counselling and support has gained prominence within the field of rehabilitation. In general, family support groups have been well received and are likely to benefit most families within the early stages of recovery from brain injury (Rosenthal, cited in Edelstein & Couture, 1984). Such groups provide opportunities for emotional support, education, and social networking (Kreutzer et al., cited in Kreutzer & Wehman, 1990). As Schaefer, Coyne, and Lazarus (1981) argued, social support groups can be defined as relationships that provide emotional, informational, and tangible help. While successful management of support groups requires facilitators who are well-versed in group dynamics and knowledgeable and experienced about the nature of traumatic brain injury (Kreutzer et al., cited in Kreutzer & Wehman, 1990), the reported benefits of family support groups are many.

According to Powell (1975), support groups offer six main benefits to individual participants. First, they offer a reference group for individuals with similar difficulties; thus, they may help decrease social isolation and increase self-esteem. Second, as information sources, support groups may aid in coping and adaptation. Third, they offer emotional support during crisis periods. Fourth, they assist the individual with lifestyle changes. Fifth, individual participants may serve as role models and so, may promote social learning and successful adaptation. Lastly, support groups serve as leisure and recreational outlets. Levine (1988) additionally stated that support groups provide a group ideology or shared values, and a sense of belongingness in a psychological
Similarly, Kreutzer et al., cited in Kreutzer and Wehman (1990) concurred that the benefits of family support groups include: (i) a sharing of problem solving, professional guidance, and information gathering; (ii) learning from peer storytelling and sharing of experience that may result in less defensiveness than traditional psychotherapeutic approaches; (iii) an accommodation of different personality styles and temperaments; (iv) an opportunity for new for social relationships, which evolve naturally through the expression of similar concerns and interests. The latter is especially important since it helps compensate for the loss of social contact that commonly follows traumatic brain injury (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Family support groups have also been developed by the consumer community (i.e., families of the brain-injured) where emotional support is provided in an environment that is less threatening and provides greater reassurance than is available in the traditional health care setting.

Other research similarly acknowledges that support groups are an effective vehicle in assisting caregivers to cope by decreasing stress, reducing social isolation, enhancing self-esteem, and promoting a sense of well-being (Acorn, 1993a; Acorn, 1993b; Cobb, 1976). Knight, Wollert, Levy, Frame, and Padgett (1980) divided self-help groups into two classes: behaviour control and stress coping groups. In behaviour control groups, the goal of group work is to elicit a change in behaviour (i.e., Weight Watchers, Alcoholics Anonymous). By comparison, stress coping groups work on helping the individual adapt to a stressful situation (i.e., bereavement groups).
Hermansen Williams (1990) researched the impact of membership in support groups upon members' perception of adjustment to brain injury. In her description of brain injury support groups and comparison to other types of self-help groups, Williams administrated a 21-item questionnaire inquiring about the impact, benefits, and description of the support group selected for study. Of the 77 members from four randomly selected state chapters of the National Head Injury Foundation (NHIF) who answered the survey, 82% percent felt their membership was helpful in their adjustment process. According to the study's reported findings, the perceived benefits of the support groups included: (i) the procurement of information on brain injury; (ii) the opportunity to relate with others who were experiencing a similar predicament; (iii) the opportunity to increase awareness about brain injury; and (iv) the chance to learn about available community resources.

In addition to family education and family support groups, family networking constitutes another type of structured approach to family intervention (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Family networking is a process of developing the extended family and social system to share the responsibility of care for the injured individual and provide mutual support (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Kozloff (1987) and others underscored the importance of actively soliciting support from extended social systems for individuals with traumatic brain injury and their families.

The aim of social networking is to foster problem solving of potential problems, as well as develop and maintain an extended support system. In order to establish the network effect, a series of group meetings is initiated, consisting of introductions,
descriptions of relationships, and education into the effects of injury (Kreutzer et al., cited in Kreutzer & Wehman, 1990). After the initial meetings, a group meeting is scheduled every three to six months to help maintain the community system. While members typically schedule more frequent meetings on an as-needed basis, it is not uncommon for subgroup gatherings to occur, particularly during times of crisis (Kreutzer et al., cited in Kreutzer & Wehman, 1990).

The value of family networking lies in providing family members with respite and in the process, preserving the often vulnerable emotional health of primary caregivers (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Moreover, its benefit rests on the fact that the group establishes a sense of cohesion, kinship, and willingness to share responsibility and, over time, no longer requires the services of a professional facilitator. This is beneficial since members develop the resources to self-manage themselves and are therefore, less dependent upon professional intervention (Kreutzer et al., cited in Kreutzer & Wehman, 1990).

Family advocacy, another family intervention approach, entails working with families (i) to help them take full advantage of existing community resources, (ii) to modify existing resources to better meet the needs of persons with brain injury, and (iii) to develop needed services (Kreutzer et al., cited in Kreutzer & Wehman, 1990). A number of organizations, such as The Head Injury Association of Toronto, the Ontario Brain Injury Association, the National Head Injury Foundation, and various local support groups, have become increasingly active in advocacy efforts. Advocacy is also provided by rehabilitation professionals, including social workers, psychologists, and case managers.
The last type of structured family intervention pertinent to this study's literature review includes family therapy. Generally performed by professional and well-trained psychologists, rehabilitation counsellors, and social workers, this type of therapy focuses on the entire family unit (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Family therapy assumes that the family is an interactive system, and that changes in one element of the system necessarily effect changes in other elements of the system (Kreutzer et al., cited in Kreutzer & Wehman, 1990; McCown & Johnson, 1993; Minuchin, 1974). It is, furthermore, based on the assumption that families develop particular behaviour patterns. The goal of family therapy is to identify adaptive and maladaptive patterns while increasing the frequency of adaptive behaviours and minimizing or eliminating maladaptive ones (Kreutzer et al., cited in Kreutzer & Wehman, 1990).

For families of the brain-injured, in particular, family therapy may play a key role in reducing feelings of grief, loss, and helplessness (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Because family roles and responsibilities are necessarily shifted as the brain-injured person's abilities and psychological status change, therapists can help negotiate and equitably re-assign responsibilities previously assumed by the injured family member. Moreover, since injury-related stress contributes to anxiety and conflict among family members, stress reduction and re-building the family into an effective team are critical therapeutic goals (Kreutzer et al., cited in Kreutzer & Wehman, 1990). Indeed, the central role of clinicians is to help families develop constructive conflict resolution strategies.
Other reported benefits of family therapy include the opportunity for enactment to occur (Minuchin, 1974). Enactment is the process by which family conflicts and maladaptive interactions are simulated in the therapeutic setting. The process of enactment allows the therapist to observe actions and reactions among family members that likely parallel processes in the home environment (Kreutzer et al., cited in Kreutzer & Wehman, 1990) while providing an opportunity for all family members to present their perspective on the causes and solutions to problems. Furthermore, objectivity is increased by soliciting views from each family member. While participation of the whole family enables the clinician to help the family develop a sense of mutual ownership for problems, efforts to cast blame and scapegoat can be identified and actively discouraged (Kreutzer et al., cited in Kreutzer & Wehman, 1990).

**Satisfaction literature**

**Quality of Service as Applied to Families of the Brain-injured**

To understand family members' perceptions concerning the degree of satisfaction with the quality of services rendered, and to enhance our understanding of family needs, this fifth and final section of the review informs the researcher and readers about literature relating to quality of service. Quality of service literature is reviewed as it relates generally to satisfaction and, more specifically, to traumatic brain injury programming for families of the brain-injured.

Marcenko, Herman, and Hazel (1992) presented a method aimed at obtaining family consensus surrounding evaluation criteria for family support programs. Twelve
family members of persons with developmental disabilities participated in a group process to identify the factors which distinguish quality family support programs. A survey designed to measure the level of importance of family generated criteria was distributed to these participating families and their family support coordinators. Families' ratings of the importance of each criterion were then compared with coordinator ratings. All recorded ideas were reviewed by the researchers and grouped by similarity of concept via content analysis. Two hundred sixty-one families and their family support coordinators were then asked to rate the importance of each factor on a 10-point scale. Analysis revealed that there was high agreement between families and their coordinators concerning the importance of all quality factors. More specifically, results indicated that the clustering of 15 quality factors centred upon: issues of qualifications, competence, flexibility, accountability, and attitudes of professionals; systemic issues such as availability, accessibility, timeliness/reliability, and consistency; and more philosophically-based concepts such as empowerment and family focus.

In the Marcenko et al. (1992) comparison of how families and their service providers rate family-generated quality of service factors, it was emphasized that families need to be involved at all program levels, namely, from program development and implementation, to program evaluation. These researchers believed that while the professional community is often in agreement with the concept of empowerment philosophically, they are frequently at a loss as to how to achieve this end in practice. Sachs (1991) confirmed the need for family involvement in planning and implementation if rehabilitation is to be effective.
In his critical reflections on fostering an integrated service network for individuals with brain injury and their families, Hoegh, cited in Finlayson and Garner (1994), documented the current shortcomings of the "medical assembly line" approach to brain injury rehabilitation. The most common experience families report is that little assistance and support are provided at the most crucial periods following the onset of brain injury. In the medical assembly line approach, there is rarely anyone to depend upon in the acute phase. Reportedly, few emergency rooms have trained clinicians who can allay the fears of family members during the acute phase. Additionally, being that the injured individual is the primary focus of treatment and care, relatively little attention is paid to families of the brain-injured. In addition to families' feeling overwhelmed by the number of clinicians in the initial phase, and frequent changes in nursing staff, in-transition clients from one phase of recovery to another are left without a responsible case manager. While allocation and utilization of financial resources are the challenges confronting decision makers who want to provide optimal clinical and community resources for brain-injured individuals and their families, the medical assembly line approach results in a piecemeal and fragmented approach to service delivery, lacking coordination between the various service modalities. In scattered, undeveloped community-based services, difficulties with access to available services becomes onerous at best, and impossible, at worst.

Hoegh, cited in Finlayson and Garner (1994), suggested as an alternative, the "product line approach" (p.399). An example of this application, the "functional-modular approach," (p.403) is applied to the delivery of clinical services. Its goal is to establish a continuum of clinical services that optimizes brain injury rehabilitation, while doing so in a
null
cost-effective and cost-competitive manner. Characterized by decentralization into small, self-directing, and self-correcting rehabilitation teams where client and family needs are in focus, a product line approach is advocated as a means of increasing product quality and ensuring job appreciation and satisfaction. The product line approach appears to hold promise as an innovative model of service delivery that radically departs from the current medical assembly line-based approach to brain injury rehabilitation. At the same time, the shift away from a medical assembly line approach implies moving away from focusing on signs, symptoms, diagnoses, and medically-oriented technicians, towards focusing on learning, growth, and professionals with more specific teaching and pedagogic background (Hoegh, cited in Finlayson & Garner, 1994).

Apart from these few studies identified under the umbrella of quality of service and satisfaction literature, there is a paucity of satisfaction literature pertaining specifically to families of the brain-injured. A review of current literature was unsuccessful in locating additional research that addresses families of the brain-injureds' level of satisfaction with the quality of existing services. The marriage between the concept of satisfaction with the field of health care, on the one hand, and rehabilitation psychology, on the other, represents another unique contribution of this research study.

Summary

The purpose of this summary is to demonstrate how the literature review, in its entirety, supports the need for this research study. Although the medical standpoint
of the issue under investigation is well represented in the literature reviewed, the psychological vantage point is considerably less remarkable. Given the scope of the deleterious effects of brain injury upon the family system, it is vital that researchers, clinicians, and educators investigate family needs on an ongoing basis, and expand upon the body of research pertaining to rehabilitation counselling psychology. Practitioners must, moreover, draw applications from the counselling psychology knowledge base to the TBI family population directly. It is vital that rehabilitation psychology further expand upon this particular knowledge base if it is to effectively assist professionals with clinical practice.

Second, there has been relatively little written about the impact of traumatic brain injury upon the family system in comparison with the more widely documented effects upon brain-injured individuals. The enlistment of the family as a tool for structuring and maximizing the survivor's environment undoubtedly represents worthy clinical and research goals; however, there is a continued need for family members to be recognized not only as service providers, but as a worthy treatment group in their own right. As psychotherapeutic interventions research focuses on the brain-injured individual, there is a concomitant need to build upon this literature for family members.

Third, although much has been written about the family's psychological adaptation to the traumatic brain injury of a family member, there is a dearth of existing data in the area of family outcome. Very few studies have characterized family outcome over time. More specifically, most research investigating emotional distress has addressed only the first year post-injury; that is, investigators have typically reported on family reactions at
certain time intervals (i.e., 3, 6, and 12 months post-injury). Time post-injury, however, is critical because of the implied relationship to various processes, including the head-injured person's recovery, his/her resumption of responsibilities, and the family's adjustment process. Recognizing the fact that most studies focus upon the acute and rehabilitation phases, the focus of this research study is on brain-injured individuals and families who are 18 months to four years post-trauma, and whose onset of injury and time since discharge from the rehabilitative facility is at least six months (and ideally beyond one year) prior to the family's participation in the study. The uniqueness of the sample characteristics, therefore, contributes to the narrowing of knowledge gaps in this particular body of literature, thus acknowledging that the transition between the post-acute to community re-integration phase represents the most serious threat to satisfaction with rehabilitative service. Future research should focus on longitudinal designs which characterize family reactions over time.

Fourth, the reviewed literature on the family's psychological adaptation to the traumatic brain injury of a loved one appears to operate within diverse conceptual frameworks. There is, therefore, a need for greater conceptual clarity in this particular body of literature between concepts like adaptation, adjustment, family functioning, and coping if the possibility of a cohesive, unified framework is to become a reality.

Fifth, one finds that research addressing the prevalence and nature of distress and impaired functioning among families of brain-injured individuals in the United States is lacking (Stiles Camplair et al., 1990). Information available from abroad may be of limited utility, given significant differences between these populations and those of the U.S.A.
(Stiles Camplair et al., 1990). In addition, researchers must employ validated assessment instruments, carefully describe their samples, and incorporate multiple sources of information in order to adequately characterize family reactions. Attention to these methodological limitations and gaps in the literature will likely improve our understanding of family responses to brain injury.

Sixth, as far as the coping literature is concerned, at least vis-a-vis families and brain injury, one finds that, though the literature reviewed has examined the issue of coping, it has not consistently drawn implications for clinicians or helping professionals. Neither has it examined the specific mechanisms utilized to facilitate adjustment. Additional research should therefore review in greater detail the strategies and interventions which will enhance family adaptation to traumatic brain injury.

Seventh, with respect to the interventions literature reviewed, most of this body of literature appears to be directed primarily towards the brain-injured client. There seems to be relatively little in the literature that speaks directly to the issue of interventions for families of the brain-injured. Additional research should expand upon the base of strategies and interventions for the purpose of assisting clinical practitioners in their practice and research of rehabilitative counselling with families of the brain-injured. The scarcity of resources in the traumatic brain injury and family literature and the tremendous challenges encountered in procuring professional journals in rehabilitation psychology indicate that further research should attempt to apply counselling and psychotherapeutic practices to the families of brain-injured population. Based upon these preliminary research initiatives, it appears that further research is needed to expand upon the narrow
and limited information base which counselling psychology offers to TBI families and rehabilitative practitioners alike.

Eighth, several criticisms may be launched against literature pertaining to the needs of families of the brain-injured. For one thing, only limited information is available on family needs following head injury. For another, most studies have addressed family needs during the acute medical phase of rehabilitation only. This research study addresses the gaps in the literature by specifically investigating quality of service satisfaction and family needs during the community integration phase of the rehabilitation process. That the study examines family needs within the specific context of service delivery and programming initiatives is also a departure from the existing knowledge base of information. Its uniqueness lies in the correlation of family needs, and services, on the one hand, and family needs and interventions rendered, on the other. Family perceptions of needs in this study are considered to be reflective of caregivers' satisfaction with rehabilitative treatment and care.

Finally, apart from a few studies identified under the umbrella of quality of service, and satisfaction literature, there is a paucity of satisfaction literature pertaining specifically to families of the brain-injured. Accordingly, additional research should address the level of satisfaction with the quality of existing services for families of the brain-injured, using a broad array of research designs and methodologies. The marriage between the concept of satisfaction with the field of health care, on the one hand, and rehabilitation psychology, on the other, represents a unique contribution of this research study. Only a handful of other studies reviewed confirmed the need for family involvement in planning and
implementation if rehabilitation is to be effective.

Overall, the literature review has identified a number of relevant areas for further research, and has substantiated the need for this research study. The purpose of this research study was to foster an understanding of families of the brain-injured's perceptions concerning the degree of satisfaction with the quality of service received. Additionally, its aim was to identify whether or not there are any gaps in service provision, and solicit recommendations as to how to improve upon the overall quality of health care to the target population.
CHAPTER THREE: METHODOLOGY

Introduction

This chapter chronologically outlines the research process from selection of site and sample, and characteristics of sample, to data collection and recording procedures, through to data analysis methods. Additionally, the study's methodological assumptions, methodological rigor, feasibility, and relevant ethical concerns are incorporated into the discussion.

The Research Methodology

Study Design: The Case Study Method

A case study may be a detailed examination of a single subject, setting, set of documents, or particular event (Field & Morse, 1985). Generally beginning with broad objectives, this type of research design usually moves to a narrower focus as the study progresses (Bogdan & Biklen, 1982). Case studies also make use of participant observation in one form or another, and often in connection with more structured methods such as interviewing or content analysis (Rothe, 1993). Rothe (1993) defined the case study method as a "detailed analysis of an individual case" (p.83). The underlying assumption of this method is that "we can properly acquire knowledge of a phenomenon from intense exploration of a single example" (Rothe, 1993, p.83). Accordingly, the method is appropriate for use in exploratory type of research (Kompf, 1991). Its suitability lies not only in the fact that the type of investigation is exploratory in nature, but also in its natural "fit" with the overall purpose of the study.
The case study method has several advantages, namely: (i) it prepares the researcher for unexpected findings; (ii) it characterizes and uncovers problems and issues and reflects how members respond; (iii) it is process oriented, allowing researchers to gather further data; (iv) its product has direct consequences for those involved; and lastly, (v) it is an opportunistic response to the observed nature of the case. Its disadvantages involve: (i) the possibility of researchers becoming over-involved in the issues of investigation; (ii) difficulties surrounding competition between various interest groups represented; and (iii) difficulties relating to the maintenance of confidentiality of data (Rothe, 1993).

**Sample Site and Selection**

The participants in this study consisted of six families recruited from a range of well-recognized and specialized organizations in the field of traumatic brain injury, with expertise in service provision to both individuals and families of the brain-injured. Site selection literature advises investigators to conduct research in a neutral setting, rather than in their "backyard" (Glesne & Peshkin, 1992; Marshall & Rossman, 1989; Field & Morse, 1985). "Backyard research" is ill-advised since conducting research in one's own institution or agency, or among friends or colleagues, may set up expectations for certain types of interactions that will constrain effective data collection (Glesne & Peshkin, 1992). With the exception of one facility, therefore, I selected neutral sites, where I neither practiced as a rehabilitation practitioner nor experienced any direct involvement with them as a family member client. The site's neutrality was anticipated to help me become vigilant as to the possibility of over-involvement in the issue of investigation.
To attract the interest of potential participants in supporting the research, I prepared an Outline of the Research Proposal, included for readers' perusal in Appendix A, and consisting of the following: (i) a letter of introduction inviting their assistance in collaborating with me in the recruitment of a participant sample; (ii) details of the research outlining the background, purpose, inclusion criteria, research methodology and procedures; and, (iii) copies of the study's Family Pre-Consent Form and Family Consent Form (Appendix B and C, respectively). Extensive reviews of the literature, discussions with potential research participants, guidance from my thesis committee, and preliminary results of the pilot study informed me that the uniqueness of the sample characteristics might pose tremendous challenges to sample procurement. In anticipation of such challenges and in order to ensure the most expeditious sample selection process, the Outline of the Research Proposal package was submitted in its entirety via facsimile to key contacts at several organizations identified as potential sites.

Of the organizations contacted, three expressed interest, and three expressed being unable to participate due to their acute care focus (not community re-entry rehabilitation mandate). Two additional facilities expressed no interest, and one denied permission to enter the organization on the grounds that a comprehensive evaluation of their family services was to be undertaken at some time in the future, and the facility did not wish to over-sample their client base.

A relationship was thus established with the primary contacts of three well-recognized and specialized organizations in the field of traumatic brain injury. While a fourth contact graciously offered her assistance in the recruitment of the sample, I
tentatively decided to defer her request on the grounds that it was assumed to be more expedient to recruit from the fewest number of organizations possible. An agreement was made with this person in which contact was to be initiated at a later date, should I experience difficulties drawing my sample from an amalgamation of the three selected sites. In this way, this fourth organization might be utilized as a back-up site in the event that forecasted difficulties arose in: (i) either locating a qualified sample, or an adequate sample size; or, (ii) in the event of an unusually high participant drop-out rate.

The process of selecting the sample occurred through independent consultation with all primary contacts of the various sites. I explained the nature and purpose of the study, as well as outlined the research methodology, and the implications to all participating clients. Through the ensuing dialogue with all contacts, recruiters committed to reviewing their respective client files in the hopes of identifying prospective participants who matched the sample characteristics.

All participants were thus selected on the basis of the following sample characteristics: (i) they were primary caregivers; (ii) they were over the age of 18 years; (iii) their injured family member was anywhere from eighteen months to four years post-trauma and had additionally been discharged from the rehabilitative facility at least six months (and ideally beyond one year), prior to the family's participation in the research study; (iv) their injured family member sustained a closed head injury (CHI) with a diagnosis of "severe" traumatic brain injury as opposed to "mild," "moderate," or "acquired brain injury"; (v) their injured family member displayed a significant level of social displacement as a result of the injury (i.e., severe difficulties with community
integration); and finally, (vi) their injured family member lived in the same residence as the rest of the family.

Using a standardized approach (Appendices B and D), the primary contacts briefly explained the purpose of the study to eligible clients, and determined their interest in obtaining further information. These key contacts then asked interested clients for permission to give their names and telephone numbers to me. Upon receiving such permission and being informed of the referral details by all organizational sites, contact was initiated within 48 hours of advisement. I introduced myself to eligible clients, described my purpose, and provided an overview of the study. At the same time, I verified that all met inclusion criteria, and conducted a brief telephone screening exercise to further determine their eligibility. By soliciting their opinion about the family services received, I was able to assess their communication abilities, level of understanding and insight, and capacity for critical thinking and reflection. If clients were willing and interested in participating in the study, I inquired about the availability of other primary caregivers within their particular family units. If the primary caregiver felt that a second member was both available and interested, together, they were invited to attend an initial orientation interview, set at a time and location of their choice.

Due to time constraints and insufficient resources at the various organizational sites, key contacts were supplying me with eligible participants on a progressive and staggered basis. To honour my time constraints and accelerate the process, I prepared an Initial Client Contact Form (Appendix E) to further assist recruiters in generating a list of eligible clients. Intended to facilitate the referral process and adherence to sample
characteristics, the form provided space to fill in (i) the name of the referring organizational site, (ii) the name and age of the primary caregiver, (iii) the telephone number, (iv) the name of the injured person and his/her respective age, (v) the name of other family members and their respective ages, and listed all of the relevant criteria of inclusion discussed previously. Key contacts were thus requested to either forward the Initial Client Contact Form via facsimile, or telephone me with the details of interested participants.

Despite such proactive measures, I continued to encounter tremendous challenges in the procurement of a qualified sample. To my dismay, I discovered that in one of the three sites selected, the organizational mandate lay outside of the inclusion criteria of this study, resulting in the identification of only two clients in a period of four months. In the second organization, only two clients were found to meet inclusion criteria, owing to the fact that this particular site had been in existence for less than two years (at time of recruitment). With only four participants identified, and all options exhausted at two of the selected sites, it was necessary to consult with the backup site.

Upon contacting this third site, a meeting was promptly arranged with the organization's Information Coordinator. An Outline of the Research Proposal was faxed in advance of the scheduled meeting to assist my contact in understanding the inclusion criteria of the research study. With sample characteristics in hand, the primary contact reviewed the organizational membership listing, and identified 11 potential participants. Using a similar procedure as that described previously for clients of the two organizational sites, four more potential informants were identified for inclusion.
The participants in this study consisted of six families (n=8) recruited from a range of well-recognized and specialized organizations in the field of traumatic brain injury, with expertise in service provision to both individuals and families of the brain-injured. My original intention was to interview one to two primary caregivers within each family unit. Of these six families, four reported having only one primary caregiver in their family unit; the other two felt that the primary caregiver responsibilities were shared amongst two primary caregivers. Consequently, four individual caregivers were selected from the single-primary caregiver family units, and two informants were chosen within the dual-primary caregiver families, thus comprising a total of eight participants.

Some literature suggests that small sample sizes of approximately 10 participants are considered adequate in qualitative research designs (Bernheimer, 1986; Ray, 1990), while other bodies of literature are based upon one case samples. Other lines of research propose that data redundancy is an accepted indicator of sample size sufficiency (Field & Morse, 1985; Parse, Coyne, & Smith, 1985). In this body of literature, redundancy is defined as repetition of statements regarding the phenomenon of study. Using this criterion of sample size, redundancy of ideas in this research study was obtained after interviewing the fourth participant. Glesne and Peshkin (1992) shed additional light on the issue of appropriate sample size in qualitative research:

How many persons must you interview? How much must you observe? How do you know when to stop? There are no magic answers. In the numbers game, depth is traded for breadth. For in-depth understanding, you should repeatedly spend extended periods with a few respondents and observation sites. For greater
breadth, but a more superficial understanding, carry out one-time interviews with more people and one-time observations in more situations. (p.27)

Families were thus selected on the basis of the following sample characteristics: (i) age/life stage, (ii) position in the family/kinship of caregiver, (iii) onset of injury, (iv) nature of the injury -- acquired brain injury or traumatic brain injury, (v) level of disability/social displacement, and, finally, (vi) family's living arrangements. The following explains the rationale for the inclusion of these particular sample characteristics and decisions made concerning the sample.

Having determined that I was interested in learning about the adult population of eighteen years or over, I therefore selected participants at this life stage. In terms of the position in the family or kinship of caregiver variable, I rationalized that in order to gain an understanding of the families' needs and their satisfaction with existing quality of service, I needed to interview family members who were primary caregivers to their loved ones. My assumption was that primary caregivers assumed most responsibility for their injured family member and would, therefore, be most knowledgeable about the quality of service delivery, gaps in the service delivery, and unmet family needs. My concern was whether or not they would be as available or committed to the research process, given their status as primary caregiver.

As far as the survivor's onset of injury is concerned, I felt this would be another variable worthy of consideration and, indeed, the literature confirmed its relevancy. My objective was to invite participation from family members who were in the community re-entry stage. The rationale for this particular characteristic is the following: The literature
generally speaks about the acute/trauma phase being characterized from onset of injury to six months; the post-acute or rehabilitation phase as six (6) months to 18 months; and, the adjustment/community reintegration phase at 18 months and upwards. I reasoned that if family members had only recently experienced the traumatic event, they would have little experience with service provision. Neither would they be in the best position to describe the quality of service, given their lack of experience with the full scope of services, and by virtue of the recency of their traumatic event. This reasoning was substantiated by the earlier review of the Marcenko et al. research (1992) confirming that some experience with the service system is necessary as a basis upon which families could formulate opinions about the elements of high quality services. Also, since the early stages of family reaction to trauma are characterized by anxiety, worry, and bewilderment (Lezak, 1986), these were thought to confound the quality of research results. Moreover, the literature is clear in stating that denial of the severity of the injury is an ongoing issue with this particular group of families until the two- or even three-year benchmark; indeed, denial assists the brain-injured individual and families to work through their adaptation process. On the other hand, I was concerned that if I selected people so far along in their adaptation process (i.e., 10 or 20 years), they might have difficulties with recall, or no longer be affiliated with any of the professional services being offered to families.

The optimal group for study, in my opinion, were those in the adjustment/community reintegration phase post-injury. At this point, family members are said to be realistic about the nature of their family member's disability and have made great strides in their adaptation process. For the purposes of this study, they have had considerable
experience in seeking help and should be in a position to offer insightful comments regarding their satisfaction with the quality of service. In fact, this is again borne in the literature, where it is argued that it is precisely in the transition between the post-acute rehabilitation phase and the community reintegration phase that "people are likely to fall through the cracks" (Kreutzer & Wehman, 1990; Finlayson & Garner, 1994): hence, the selection of participants whose injured family member was anywhere from eighteen months to four years post-trauma, and additionally discharged from a rehabilitative facility at least six months, and ideally beyond one year, prior to participation in the study.

I then entertained the question of whether to select participants with traumatic brain injury, or acquired brain injury, and opted for the recruitment of the former. People who sustain an acquired brain injury (e.g., brain tumour, aneurism) allegedly do not have access to the gamut of services to which those with traumatic brain injury are entitled. By contrast, individuals with traumatic brain injury do have access to private rehabilitation and case management services. I reasoned that it would be preferable to recruit family members of the traumatically brain-injured since the scope of service would allegedly be better for such families. If a better service were proven to be wanting, the case would concomitantly be proven for lesser servicing extended to those with acquired brain injury.

The level of disability or social displacement was considered as another important variable worthy of consideration. The literature is clear on the fact that families adjust in similar ways, regardless of the severity of the injury (i.e., "mild", "moderate", or "severe"). It is also clear on the fact that the greater the severity of the injury, the greater the sense of family burden, stress, strained family relationships, and need for intervention.
This is particularly so if the family's pre-morbid functioning (i.e., family's functioning prior to the traumatic event) and coping resources are found wanting (Sachs, 1985). However, since severity of injury is fairly arbitrary and not particularly relevant to long-term outcome, I opted to select family members whose loved one had a high level of disability/social displacement (i.e. significant level of difficulties with community integration). In a similar vein, I opted for participants whose injured family member sustained a closed head injury (CHI), with a diagnosis of severe traumatic brain injury. I hypothesized that their constellation of experience was more accentuated than the mild or moderate family groups.

Finally, I felt I needed to attend to the question of the family's living arrangements. Was the brain-injured individual living alone, in a residential community home, or with family? On this question, I reasoned that there was a greater likelihood of learning from the most knowledgeable caregivers if the caregiver lived under the same roof as his/her injured family member. It was additionally assumed that such a primary caregiver would be considerably more stressed, and therefore most aware of family needs, as compared to someone whose living arrangements were independent and separate from that of their loved one.

As I journeyed through the sublime and rather enigmatic thesis process, I began painstakingly to acquire greater, more in-depth learning, reflection, and insight. Interestingly, I began to realize the inherent limitations of the above-mentioned assumption. A primary caregiver who lives separately and independently from his/her injured family member may not necessarily reflect a lack of caring, concern, or knowledge
for the injured family member. In fact, as one professional colleague succinctly put it,
"How does one know that the most resourceful families aren't the ones who fully support
their brain-injured family members' independent living? Where is it written that
independent living arrangements can't foster adaptive coping and adjustment in the injured
family member, or promote the restoration and healing of family relationships, where they
have gone awry as a result of brain trauma?" Although I honestly do not know the answer
to these questions at this time, I at least have a new looking-glass!

According to Polkinghorne in Valle and Halling (1989), the participants chosen for
phenomenological research must fulfil two requirements: (i) they must have had the
experience underlying the issue of investigation; and (ii) they must have the capacity to
provide full and sensitive descriptions of the experience under investigation. In addition
to these criteria, informants needed to be primary caregivers, articulate in English, able to
provide consent, available for the entire duration of the data collection and analysis period,
and capable of critical thinking and reflection.

The lengthy recruitment period of five months, and the numerous challenges
encountered in the process, occurred for several reasons. Throughout the recruiting
phase, the key contacts at the various organizational sites made a total of 30 telephone
calls. During these telephone conversations, 17 of 30 clients (57%) did not meet the
inclusion criteria for this study. Ineligibility was largely a function of one main sample
characteristic, the one specifying that participants must have an injured family member
anywhere from eighteen months to four years post-trauma. There were four of 17
ineligible clients (24%) whose family member had sustained injury prior to 18 months
(mean of 3.1 months post-injury), and five of 17 clients (29%) whose relative was well
beyond the four years post-injury criterion (mean of 16.6 years post-injury). Another
three of 17 ineligible clients (18%) were discounted on the grounds that two clients had
sustained "moderate" brain injuries (12%), and another was diagnosed with "mild" injuries
(1%). Another ineligible client was eliminated from participation due to results on the
Community Integration Questionnaire indicating a level of severity far greater than the rest
of the sample. To ensure worthy and meaningful results, only those with comparable
sample characteristics were selected for inclusion. The unique cluster of inclusion criteria
in this research study, therefore, seemed to fall outside the scope of the organizational
mandates of sites selected for sample recruitment. This was surprising in view of the fact
that colleagues in the rehabilitation field recommended these particular organizations to
suit the study's sample parameters. That these difficulties accrued may in itself be
testimony to the fact that the sample described is a worthy segment for further
investigation.

Other related difficulties stemmed from injured individuals being (i) only recently
discharged from the rehabilitative facility, instead of at least six months (and ideally
beyond one year) prior to the family's participation in the research study, or, (ii) still
undergoing rehabilitation at time of study. As mentioned, four of 17 ineligible clients
(24%) had a family member who had sustained injury prior to 18 months (mean of 3.1
months post-injury), and were thus still in rehabilitation. Such families were discounted on
the grounds that they were presumed not to have adequate experience with family service
to ensure meaningful participation. Of nine ineligibles who reported having inadequate
experience with family service, it is interesting to note that four were also unwilling to discuss the traumatic event. Of these, three were disqualified because they were not deemed to be primary caregivers by their own self-definition, and lack of ability to describe the family services received.

Second, five of 13 eligible clients (38%) chose not to participate in this study. Among these five clients, three reported being not interested, one lacked the time, and one reported feeling too stressed.

Third, the larger socio-political context in which the study was conducted (i.e., radical restructuring of health care reform and dwindling funds) directly impacted upon, and contributed, to delays in the recruitment process. Delays in sample recruitment were thus a function of the organizations' lack of financial resources and time constraints. One of my key contacts, for instance, worked two to three days per week on a part-time basis. Given that there were no additional organizational resources available to hasten the recruitment process, this meant unfortunate delays in response-time (i.e., in the amount of time available in her review of client files, contact of clients, return of messages, etc.)

Another organization was undergoing changes in their organizational structure, resulting in the key contact's feelings of being overwhelmed and burdened vis-a-vis her recruitment task. Yet another organization who chose not to participate offered this explanation that bears directly on the issue of organizational resources: "As with all research, we must be concerned about the needs of our patients and the needs that arise as a result of their participation in research projects. Should treatment needs or concerns arise in any of these patients and families as a result of this study, we currently do not have a staff"
member who will be able to serve (due to time constraints) in an advisory capacity."

Finally, my own decision to pursue neutral organizations, rather than one in which I was affiliated, contributed to delays in the recruitment process. In three of the four neutral organizations in which I sought sample recruitment, the groundwork for rapport needed to be established. There were also the usual difficulties of access, which are of course compounded when dealing with more than one organization. As Glesne and Peshkin (1992) argued, access is a process:

If the study involves some sort of organization or agency, then you must first make contact with "gatekeepers", the person(s) who must give their consent before you may enter a research setting, and with whom you must negotiate the conditions of access. Making contact can be complicated, involving different persons at different times. (Glesne & Peshkin, 1992, p.33)

As far as sampling procedures are concerned, the type of procedure that has been described and utilized is non-probability sampling. Quantitative research designs generally rely upon probability sampling, that is, "elements are chosen for study from a population on a basis of random selection with known non-zero probabilities" (Babbie, 1992, p.230). In my qualitative research study, I utilized non-probability convenience sampling since the participants' selected had unequal likelihood of inclusion in the study. Non-probability sampling involves studying a small subset of a larger population in which many members of the subset are easily identified, but the enumeration of all of them would be nearly impossible (Babbie, 1992). For this reason, the sample is said to be purposive or judgemental, in that "the researcher utilizes his or her own judgement in the selection of
sample members" (Babbie, 1992, p.233). Although this type of sampling is known to increase the probability of response, results will not be generalizable (Babbie, 1992).

**Ethical Considerations**

Following approval from the thesis committee, permission to conduct the investigation was granted from all concerned parties, including the various organizational sites, the Research Ethics Committee of Brock University, and all participants.

I reassured families that participation in the study was entirely voluntary, and that the outcome of their decision would not, in any way, impact upon the quality of rehabilitative care that they, or their loved one, would receive, either at participating organizations, or elsewhere. At the beginning of all orientation interviews, I reiterated the nature of the research, its purpose, and procedures, and obtained participants' written consent (Appendix C). I additionally requested that participants complete the Community Integration Questionnaire, a brief, reliable measure of an individual's level of integration into the home and community (Willer, Ottenbacher, & Coad, 1994), and the Family Participant Questionnaire, as a means of further ensuring they met inclusion criteria. I then informed participants that they could withdraw from the study at any time and without any penalty (Appendix B). Finally, all participants were advised that there were no anticipated risks associated with participating in the study, and neither were there any direct benefits to them other than benefits associated with an opportunity to express personal thoughts in the presence of attentive listeners.
Confidentiality was facilitated by conducting interviews in a comfortable and private location, of participants' choice. Informants were assured that all information relating to either themselves or their family would be kept confidential, and that no information would be released or printed that would disclose their personal identity without permission. During the first interview, written consent was obtained from participants regarding the tape-recording of interviews. Participants were further informed that the interview tapes would be destroyed upon completion of the study (as indicated in the Family Consent Form, Appendix C).

I was particularly aware of the need to exercise caution in causing the least psychological inconvenience possible, given the potentially heavy, emotion-laden content of the issue under investigation. I minimized subjects' psychological stress/discomfort by asking all key contacts to arrange for therapists to follow-up with their clients shortly after both interviews, if necessary (i.e., the initial orientation interview and the second private interview). This was to ensure that old wounds had not been opened and left unattended. I also offered to make arrangements to refer interviewees to appropriate clinicians or sources of information. Finally, within 48 hours of completing a private interview with all participants, I made a courtesy follow-up call, the purpose of which was to assess whether the participant was in need of clinical intervention. A commitment for debriefing was made upon availability of results and completion of study. Any information yielded from this study, which may be of assistance, would be shared and communicated with the participants, Brock University, all participating facilities, and any other interested parties.
Being a family member of a loved one who sustained a brain injury, I felt it was vital to be aware of the possibility of over-identification with participants and the concomitant risk of introducing subjective bias into the research process. The risk of over-identification was inherently compounded by one of the central disadvantages of the case study method, namely, the possibility of over-involvement in the issue of investigation (Rothe, 1993). The use of a semi-structured, open-ended interview guide, however, minimized the introduction of bias during data collection, as did my concerted effort to focus and attend on truly hearing the informant's words, as preparation for the interview. As additional measures of precaution, I recruited family participants randomly in terms of the position in family/kinship of caregiver variable. I might have had greater difficulty in controlling subjective bias, for instance, had I sought out participants in the same kinship relationship, vis-a-vis their brain-injured loved one, as myself. Furthermore, by tape-recording the interviews and transcribing them verbatim, I was able to interpret participants' experience using their own words.

As an additional measure of precaution, I retained a graduate candidate to review two random selections of the analysis, and perform independent and unbiased critical analysis. The candidate was given guidelines in the use of Colaizzi's method of protocol analysis to ensure that both of us were adhering to the same data analysis methods. Although the candidate's naming of themes differed slightly from my selections, the essence of the analysis and the meanings derived from participants' words were very similar.
An ethical dilemma arose when interviewing two family member participants within one family unit. How much information should I be willing to share with the other, when full assurances of confidentiality were made and norms for confidentiality represent the very core of the ethical behaviour of researchers? What to do when receiving conflicting information from two caregivers from one family unit? Were norms for confidentiality extended to members of the same family? In the interest of staying true to my word, I maintained confidentiality as much as possible, even when it was clear that divulging a conflict or difference in two family members' perceptions might elicit a richer and fuller account of the family's "story". I later decided that my original perception of an ethical dilemma was in fact a moot issue. By virtue of my ethical responsibilities as researcher, I was ethically bound to conceal differing family perceptions when interviewing dual-caregiver family participants. Notwithstanding this ethical obligation, however, I do not believe I sacrificed richness or truth value. Keeping norms for confidentiality, under these conditions, would simply engender more rapport and trust in the informant-researcher relationship. Such trust would in itself be the very condition for rich and meaningful data. Treatment of ethical considerations is further discussed in the section on Methodological Rigor of this chapter.

Another ethical consideration arose, particularly during data collection. I became uncomfortably aware that I was the principal beneficiary of the research. It occurred to me that participants were generously offering their personal "stories" and their time, with little direct benefit, other than the possibility of airing their feelings in a climate of acceptance. Indeed, for all, participation in the study seemed to be therapeutic in terms of
providing an opportunity to be listened to, and to have personal views validated. However, I felt that I needed to express my appreciation by giving back in some way, beyond merely a future promise of the research serving emancipatory ends of important heuristic value. It was hardly considered adequate to offer a presentation of findings to the group and to the participating facilities upon completion of the study, although this was offered and delivered, as committed. Somehow the promise of such negotiated exchange at a later date hardly seemed to compensate participants adequately for their involvement in the present. If I could at least provide a warm therapeutic climate filled with support and praise, then perhaps I could compensate participants for their generosity, and express my genuine appreciation. Playing a clinical role would indeed serve to promote more immediate rewards for participants. Yet, as will be discussed in further detail in The Researchers' Role, Relationships, and Experience, such behaviour would be construed as overly directive and controlling, and would thus represent a canon by which the credibility and trustworthiness of the entire study would be called into question.

**Pilot Testing**

According to Glesne and Peshkin (1992), the purpose of pilot testing is to prepare the researcher for the data collection process. It allows investigators to explore the research problem, research process, interview questions, observation techniques, and rehearse the role as researcher. To ensure that I had clearly, concisely, and accurately communicated my research questions to participants, I pilot-tested both the questionnaire and semi-structured interview instrument prior to proceeding to conduct interviews. I
requested that a group of four family members in similar circumstances to those being studied provide feedback. To ensure that I had addressed content issues thoroughly, I ran a second pilot test with a group of four rehabilitation counsellors.

A package consisting of three specific materials was presented to pilot test participants. One document outlined the nature and scope of the research, its purpose, and process. A second item outlined instructions for critiquing and commenting on possible interview questions. The pilot group, consisting of family members and rehabilitation practitioners, were asked to carefully critique the instruments according to the following criteria:

a. adequate and relevant background information;
b. clarity of questions;
c. grammar usage;
d. ease of comprehension, reasonable level of difficulty of questions;
e. approximate time required to respond to questions; and
f. overall organization and presentation of the document.

Lastly, a feedback form was provided which allowed the pilot test participants to provide feedback on the research questions in terms of the specific guideline criteria. This complete package is presented in Appendix F.

Upon completion of this procedure, the comments were returned via facsimile to the researcher. Questions were refined according to the constructive feedback provided by the pilot test group. Due to the paucity of qualified participants during the recruitment phase, all pilot data of family participants were later incorporated into the study. The use
of pilot testing continued throughout the duration of data collection, as written information lent additional support to the verbal interviews of caregivers. Via triangulation, pilot testing proved to be an effective means of further substantiating the data, and was utilized to enhance the trustworthiness of findings, and therefore, establish the validity of data. Any deviations in the data collection process owing to the inclusion of pilot participants, be it in the research process itself or in the use of interviewing techniques, will be elaborated upon and substantiated in the following section.

Data Collection and Recording Procedures

The data collection methods employed are ones that dominate traditional qualitative inquiry, namely: observation, interview, and document collection (Glesne & Peshkin, 1992). My own personal observations and experience supplied a further dimension to the data. Within this scope of interpretive research, I chose techniques that would likely (i) elicit data needed to gain an understanding of the phenomenon in question; (ii) contribute different perspectives on the issue; and (iii) make effective use of the time available for data collection (Glesne & Peshkin, 1992). The use of multiple data collection methods contributes to the trustworthiness of the data (Bogden & Biklen, 1982; Glesne & Peshkin, 1992). This practice is commonly called triangulation and may also involve the incorporation of multiple data sources, investigators, and theoretical perspectives in order to increase confidence in research findings (Denzin, 1988).
The Researchers' Role, Relationships, and Experience

Prior to describing the data collection methods in further detail, I would like to acknowledge the central feature of data collection. As researcher, I became the primary instrument of data collection. This posed several unique challenges, the first being epistemological in nature and facing the interpretative research tradition in general. If I am the instrument by which knowing will occur, how do I know that my own instrument is indeed credible or trustworthy? On another level, and in a related fashion, the role of researcher necessitated a transformation of my view of self as clinician to that of researcher. Yet, I experienced tremendous challenges leaving behind the counsellor role and entering the researcher role (Krefting, 1989). Although I had been forewarned about such difficulties in preparatory reviews of the literature, I learned they proved miserably inadequate in the face of reality. Being a professional counsellor who was trained to be empathic, supportive, and attentive, I initially had a tendency to exert influence and control over the course of the interviews. I found it particularly onerous to shift from a counselling mindset in which one offers therapeutic interventions as positive feedback, reinforcement, and support, to a research mode characterized by neutrality, non-directiveness, and a lack of subjective bias. Indeed, differences related to the contrasting goals of research versus counselling are well documented (Meara & Schmidt, 1991).

In the initial interviews, I had attempted at every opportunity to remind myself to refrain from engaging in the counsellor roles of reflecting, summarizing, paraphrasing, or responding to content, feeling, or meaning (Carkhuff, 1993). Participants may agree with an investigator's restatement even if it is incorrect instead of clarifying what they really
mean (Field & Morse, 1985). All of these counsellor roles and behaviours were inimical to the realm of research, where any leading, intervening, or directing behaviour on the researcher's part would be construed as introducing subjective bias into the research process, thus threatening the very credibility and truth-value upon which research findings lay.

To safeguard the quality of the study and ensure my commitment to high standards of scientific rigour, my thesis committee encouraged me to refrain from engaging in counsellor behaviour; indeed, I was advised to pose my research questions, probe for additional information, and request clarification, if required. A recommendation was made to refrain from intervening, even when the participant was clearly off-topic. Although this method of interviewing felt somewhat artificial to me and lacked a quality of aliveness or genuineness (Corey, 1986; Gilliland, James, & Bowman, 1989), and additionally required an incredible degree of self-discipline, I embraced the recommendations of my thesis committee and consistently continued to use this technique throughout data collection.

As researcher, I was additionally challenged by the need to be ever conscious of my verbal and nonverbal behaviour, and decidedly more attuned to my behaviour and its impact (Glesne & Peshkin, 1992). To add a further dimension to the mental gymnastics and juggling act, I needed to integrate within my researcher persona my role as learner. According to Glesne and Peshkin (1992), "You do not come as an expert or authority. If you are so perceived, then your respondents will not feel encouraged to be as forthcoming as they can be... In this, as in so much of research, you need to find yourself, your style, so that you will learn what works for you" (p.36-7).
I attempted, at every opportunity, to remind participants that the researcher-informant relationship was a non-hierarchical, egalitarian one, and that participants had inherent power in the relationship. Meeting times were scheduled at participants' convenience but, more significantly, participants determined what and how much they shared with me. I purposely chose to conceal my identity as a rehabilitation practitioner and family member of a brain-injured individual since such identification might have prevented participants from disclosing information assumed to be known. "Casting yourself as a learner correspondingly casts the respondent as a teacher" (Glesne & Peshkin, 1992, p.81). Every participant, on at least one occasion, questioned if he/she were sharing what I wanted to hear, or otherwise attempted to prompt me to define or narrow the research questions for them. I empowered informants by reminding them that I wanted to hear whatever they felt was important for me to hear in order that I might understand their experience.

Because I was the primary research instrument, the study's quality was closely connected to my competence as investigator (Field & Morse, 1985). Interviewer attributes that may contribute to successful interviews have been identified (Babbie, 1992; Glesne & Peshkin, 1992). Good interviewers (i) are anticipatory (i.e. well-prepared and proactive); (ii) have an ability to establish rapport and engender trust; (iii) demonstrate a willingness and openness to embrace their role as learners; (iv) possess excellent analytic, reflective, and creative abilities; (v) have strong listening and attending skills, (vi) possess qualities of being non-reactive, non directive, and supportive of a therapeutic environment; and, (vii) make appropriate use of probes. Generally, good researchers facilitate openness
by being non-threatening, warm, and caring. Many of these attributes correspond with the skills of a good clinician (Lipson, 1991). As Cormier and Hackney (1993) discerned, the characteristics of effective helpers include: self-awareness and understanding, good psychological health, sensitivity, open-mindedness, objectivity, competence, trustworthiness, and interpersonal attractiveness.

Despite my attempt to remain aware of these personal and professional attributes and to build upon them through ongoing reflection, the phenomenological approach proved to be challenging for both investigator and participants of this study. It was difficult to achieve experiential data of the depth and richness needed to provide adequate evidence for my descriptive account of the experience of families of the brain-injured. It was sometimes difficult for participants to recollect and relay their experiences with the traumatic brain injury of their family member.

A second obstacle to data collection was participants' uncertainty and, at times, misinterpretation of what was expected of them. They sought reassurance in questions such as "Is this what you want?" As discussed previously, it proved difficult to mitigate between being evasive, and being helpful without being leading.

Finally, and perhaps the most challenging, was focusing participants' attention and description on the experience under study. Confounding talk and/or exclusive focus on their injured family member (rather than the family services received, which was the subject of investigation), occurred all too frequently. At times, descriptions of feelings and situations were so interrelated with experiences with the loved one that it was difficult to discern which experience was the focus of attention. The life experiences of these
participants were so enmeshed that it was difficult for them to isolate the one experience of interest to the researcher and to describe it in isolation of other experiences.

It was on this basis of roles and relationships that the data collection methods were undertaken. Family participant interviews, observation, and document review, as well as my fieldnotes corresponding to each of these sources of data will now be described.

**Initial Orientation Interviews**

All interviews were conducted at a time and location of participants' choice. Every effort was made to encourage participants to select a physically comfortable, relaxed, and pleasant environment. At our first orientation interview, I met with one or both family participants from a single family unit to reiterate the nature of the research, its purpose, and procedures, and reassure participants of norms for anonymity and confidentiality. I also informed participants that they could withdraw from the study at any time and without any penalty. Moreover, I reassured families that participation in the study was entirely voluntary, and that the outcome of their decision would not, in any way, impact upon the quality of rehabilitative care that they, or their injured family member, would receive, either at the various participating organizations or elsewhere in the larger rehabilitation service-provision community. All participants were advised that there were no anticipated risks associated with participating in the study, and neither were there any direct benefits to them other than benefits associated with an opportunity to express personal thoughts in the presence of an attentive listener. In addition to clarifying any outstanding questions or concerns for participants, I obtained participants' written consent
from those interested in pursuing involvement.

Beyond establishing the rapport and, ultimately, trust required for a good informant-researcher relationship, the aim of the orientation interview was to gain an understanding of: (i) participants' demographic data; (ii) the history of the family (i.e., family membership, the nature of family relationships, pre- and post-injury status); (iii) details of the injury; (iv) information relating to the type, use, and need of family services utilized, and (v) the degree of social displacement/level of community integration of the injured family member, as measured by the Community Integration Questionnaire (Willer, Linn, & Allen, 1993a; Willer, Ottenbacher, & Coad, 1994; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993b). This objective was accomplished by requesting participants to complete two brief questionnaires, the Community Integration Questionnaire and the Family Participant Questionnaire, both of which will be discussed in the following sections, and are included in Appendix G and H, respectively.

**Family Participant Questionnaires**

Preliminary data were gathered during the initial orientation interview pertaining to demographics, the history of the family (i.e., primary caregiver, family membership, the nature of family relationships, pre- and post-injury status), details of the injury, and information relating to the type, use, and need of family services utilized. The questionnaire was intended to supply me with preliminary information and to act as a springboard for additional data collection. Content issues for the questionnaire were developed from the literature reviewed in Chapter 2, and the questionnaire items consisted
of closed-ended questions, which are allegedly best for obtaining this type of data (MacMillan & Schumacher, 1989).

Some portions of the questionnaire were modelled according to The Caregiver Information Support Link (CISL), a part of The Ontario Brain Injury Association's information network, which includes listings of identified services to persons with traumatic brain injury, and whose aim is to assist persons who live with the effects of a traumatic brain injury. No validity or reliability data are available for the CISL when only selective portions are chosen for inclusion. Because the Family Participant Questionnaire was designed specifically for this study, there are, additionally, no data available on its reliability. However, a pilot study of the Family Participant Questionnaire, conducted with a group of four family members in similar circumstances to those being studied, and a group of four rehabilitation practitioners who were experts in the field of traumatic brain injury rehabilitation confirmed the instrument's validity. Specifically, the use of an expert panel that included consumers of rehabilitation services points to a high likelihood of content validity. A copy of the questionnaire is included in Appendix H.

The Community Integration Questionnaire (CIO)

Commonly used expressions that describe the goal of rehabilitation are community integration, community reintegration, and community re-entry (Kreutzer & Wehman, 1990). Despite numerous articles and several books devoted to the concept, however, there appears to be an absence of a clear definition. The term is rarely clarified or anchored operationally (Willer, Linn, & Allen, 1993a) and the problems of defining and
measure community integration have been addressed by several researchers (Rosenthal, Griffith, Bond, & Miller, 1990; Kreutzer & Wehman, 1990). Few instruments specifically assess handicap (Willer et al., 1993a).

To gather data on the degree of social displacement/level of community integration and to ensure appropriate comparability of data, I requested that participants complete the Community Integration Questionnaire (CIQ) (Willer et al., 1993a; Willer et al., 1994). The instrument is designed to assess home integration, social integration, and productivity in persons with traumatic brain injury. Intended as a brief, reliable measure of an individual's level of integration into the home and community (Willer et al., 1994), the CIQ was developed by a small group of experts interested in characterizing the experience of TBI individuals in the community, particularly after the acute rehabilitation phase. The instrument is normally completed by the injured individual, with the assistance of a caregiver or, alternatively, by a caregiver familiar with the person's health status and social activities (Willer et al., 1994). For the sake of expediency, family member participants were requested to complete the form in proxy during the initial orientation interviews of this study.

The Community Integration Questionnaire comprises three subscales (home integration, social integration, and productivity), and consists of a total of 15 questions. The overall score, which represents a summation of the scores from individual questions, ranges from 0 to 29. A higher score indicates greater integration, and a lower score reflects less integration. All participants had unique scores, ranging from a lower limit of 10 to an upper limit of 20, with a median score of 14.2, and a mode of 1. Comparative
testing of the CIQ instrument (Willer et al., 1994) revealed that the mean CIQ score for the TBI group is 13.02 (SD = 6.02). For the control group (non-TBI group), the mean CIQ total score is 20.71 (SD = 3.21). No categories have been established to determine which scores represent a mild, moderate, or severe degree of social displacement. Total scores from the CIQ are normally distributed, both when completed by individuals who are not disabled and individuals who are disabled as a result of traumatic brain injury (Willer et al., 1994). The instrument and scoring guidelines are included in Appendix G.

Because the CIQ represents a finite set of indicators of community integration and, as such, does not encompass all possible indicators of integration, it is recommended that the instrument be used in concert with similar assessments of impairment, disability, and environmental barriers (Willer et al., 1994). Due largely to time and resource constraints, it was deemed unnecessary to heed their advice concerning the use of the instrument in conjunction with other similar assessments. The rationale for this departure from application norms is that, in this study, the CIQ was merely utilized as a screening device to ensure eligibility of participants. It was not used for clinical assessment purposes. It is important to acknowledge, therefore, that a question remains as to the impact of utilizing the CIQ in this manner in terms of its effect on researchers' validity and reliability data (Willer et al., 1994), the subject of which is treated in the following section.

Validity refers to the extent to which an instrument measures what it purports to measure. According to Babbie (1992), there are numerous yardsticks for determining validity: face validity, criterion-related validity, content validity, and construct validity. Although the validity of the CIQ is yet to be clearly established (Willer et al., 1994),
results of comparison between the brain-injured and non brain-injured population are suggestive of the instrument's validity. As reported in Willer et al. (1994), individuals with brain injury are significantly less likely to be integrated than those who have not experienced TBI. Moreover, the development procedures and use of the expert panel are likely to increase the likelihood of content validity (Willer et al., 1994).

Reliability refers to whether a particular technique, applied repeatedly to the same object, would yield the same result each time (Babbie, 1992). The instrument was found to have high test-retest reliability (Willer et al., 1994) since coefficients for the three subscales were .91 for individuals with TBI, and .97 for family caregivers.

**Semi-Structured Interviews**

The written informed consent obtained from all participants permitted the tape recording of all interviews, discussion of interviews, as well as use of participants' first names within the body of the study and discussion of results. Within a couple of days of the initial orientation interview, I scored the Community Integration Questionnaire, and reviewed the Family Participant Questionnaire to determine eligibility. Within one week of the orientation interview, I telephoned participants to confirm eligibility, and informed them of the second phase of scheduled interviews. A one-week interval time frame was selected to ensure a sense of continuity, both for the informant to remember the purpose of the study, and the researcher to recollect participants' stories. The purpose and processes of the second phase of the data-gathering process were explained, and a meeting time was convened as close to the initial meeting as possible. I had prepared participants
to expect our interviews to be one to two hours in length. The briefest was 45 minutes; the longest in excess of four hours.

To set the stage for the collection of adequate experiential data, the interview guide facilitated participants' retrospection.

From the moment you first heard the news of your family's member's trauma, you entered a whole new world. Suddenly, your family member was thrust into a gamut of services you probably never even heard of before, let alone experienced. By virtue of your status as a family member, you were introduced to, and entitled to a number of different services to help you deal with the experience, and to help you adjust and cope with your family member's traumatic brain injury. (Family Interview Guide, p.1)

Accompanying interview notes suggested ways of extending the range, depth, and specificity of participants' descriptions. When participants are encouraged to retrospect, they are more likely to recall a response to the situation of study, rather than respond to the interview situation (Merton, Fiske, & Kendall, 1990).

In the semi-structured interview, a series of concise, clear, and focused questions are developed in advance, and incorporate a series of structured questions (Rothe, 1993). All questions are worded and ordered exactly the same for all respondents so that all are asked to remember the same events (Bernheimer, 1986). According to Rothe (1993), the questions should be: (i) easy to answer, (ii) yielding needed and useful information, (iii) interesting to both researcher and informants, and (iv) selected from a review of literature, clinical experience, and/or personal experience. The use of probes is helpful in leading
informants into providing greater depth and breadth for answers (Rothe, 1993).

In the semi-structured interviews with individual family members, the participants were requested to respond to each question with as much detail and in as much depth as possible. They were also informed that they could take as much time as needed to respond to the questions, and that there would be little interruption throughout the course of the interview. I had anticipated that it might be difficult for participants, all of whom had experience with highly structured and directive clinical interviews, to participate in such a different form of interview. I felt that by explaining the reasons for minimal interruption, I could allay any potential awkwardness a one-way conversation might engender. Such pre-framing on my part was presumed to provide participants with the resources needed to cope with the discomfort. For the most part, this was indeed the case. In an effective interview, both researcher and informant feel good, rewarded, and satisfied by the process and the outcomes (Glesne & Peshkin, 1992).

An open-ended question approach permitted participants to inform me of what I had intended to learn, in their own words, and without any subjective bias on my part. Questions were open-ended "to give informants the freedom to respond in their own words" (Field & Morse, 1985, p.67; MacMillan & Schumacher, 1989). A non-directive approach to interviewing gave participants the opportunity to discuss matters of central significance to themselves, rather than those presumed to be important by the researcher (Merton et al., 1990). I explored a few general topics to help uncover the participants' perspectives, but otherwise respected how participants framed and structured their responses. In fact, this is a fundamental assumption of qualitative research: The
participant's perspective on the social phenomenon of interest should unfold as the participant views it, not as the researcher views it (Marshall & Rossman, 1989).

It was my hope, therefore, that families would inform me about the types of family services they may have had a chance to utilize, outside of those offered by the participating organizations. Additionally, I hoped that participants would inform me as to whether or not they had actively sought such services. I decided it would be best to allow family members to inform me as to the scope of professional services for families, rather than constrain the process of inquiry by my own preconceptions/definitions of what service to families of the brain-injured population includes.

The underlying rationale was that family members are in the best position to identify the services. My preconception was, however, that the rehabilitation services offered to families would consist predominantly of those involved in education, counselling, and support services to families. For this reason, I assumed that family members would identify acute and post-acute health care facilities, case management services, social work, and counselling, as services that fall within the domain of service to families of the brain-injured. It was my hope that informants would reveal a snapshot of competent practitioners with solid professional knowledge and expertise in the rehabilitation field as well as specific expertise in assisting family members to cope with traumatic brain injury and its effects.

Throughout the entire interview process, I endeavoured to convey a sense of acceptance and respect for participants' feelings. As I posed the research questions, I listened attentively to participants' stories, and then asked more specific, directed
questions concerning particular aspects of service (e.g., availability, frequency of service, communication, professional behaviour, etc.), gaps in the service delivery, and emergent needs that might have remained unfulfilled. I adopted the stance of interested listener, exhibiting warmth and empathy for the experiences of informants. I did not voice personal opinions about, or sentiments towards, the content of our interviews, although I initially had difficulties refraining from reflecting and summarizing, as discussed. Probes were cautiously utilized to learn about participants' perceptions whenever data appeared thin and superficial (Field & Morse, 1985).

To prevent the possibility of family members within one family unit from sharing the results with one another and therefore biasing the responses, I requested that members not discuss their private interviews with their family. I indicated that they would have an opportunity to do so when their participation in the study was complete.

Member Checks with Family Participants

A member check is both an assurance of validity and reliability in the research process, whereby information is cross-checked to ensure that the researcher has accurately understood and heard participants' stories. Due to limited resources and time constraints, my thesis supervisor and I discerned that the most expeditious way to facilitate the member checking process was via telephone. Furthermore, it was decided that it was only necessary to conduct member checks with two of the eight participants. Given this particular application of member checks, the need for impartiality and randomness in the selection of the participants for member checking was imperative. In this vein, I devised a
system that could withstand the test of scientific rigour. Participants' names were thus correlated with sequenced numbers ranging from one to eight. With the numbered pieces of folded paper in hand, I tossed them into a hat, and mixed them. Two of the eight participants were thus randomly selected for member checking.

It was reasoned that if there were indeed gross misrepresentations in the data, two member checks would be sufficient to identify a faulty pattern and dictate the need for a revision in the process. Hence, following the second semi-structured questionnaire and private interviews, two randomly selected participants received a telephone call requesting their participation in the process. In this way, participants were given the opportunity to confirm that the information they provided, as well as the interpretations made by the researcher, were complete and accurate. With the individual's transcript and my analysis of the interview in hand, I called the respective participant at the appointed time. To aid the informant with recall and help fixate our previously conducted semi-structured interview into a meaningful context, I reviewed with the participant what I considered to be his/her significant statements. Such extracted statements were drawn directly from the participant's own words in the transcript of the interview to avoid the possibility of subjective bias. I then presented the themes identified from our interview conversation, and requested feedback as to their accuracy. I also encouraged the participant to tell me whether he/she agreed or disagreed with my interpretations. If the participant disagreed, I asked him/her to let me know where he/she disagreed.

Following the review of data analysis, any changes to either the participants' information or my own interpretation, were thus made accordingly. For the most part,
both participants demonstrated strong and unequivocal agreement with their previous statements, and even substantiated the statements by stating additional examples, or restated agreement using similar words. At other times, one participant elaborated in greater detail on certain points raised previously, as will be discussed in the fourth chapter on findings. Interestingly, in both cases, there were no disagreements, despite the opportunity granted for self-expression and their evident comfort with me, as researcher -- once again, confirming the validity of the data.

**Observation**

Observation, as a method, occurred throughout all fieldwork, and was recorded through detailed fieldnotes. I remained attuned to opportunities to gather information throughout the course of the study (i.e., informal conversations and preliminary meetings designed to facilitate the process of gaining entry, informal conversations with key contacts at each of the participating organizations, introductory telephone calls with participants, initial orientation interviews, private interviews, and ongoing telephone conversations with participants). Such opportunities provided a context for further data collection and for analysis.

**Document Review**

Review of relevant documents was an additional data collection strategy that provided contextual information. Such documents included a review of the organizational brochures of the various participating organizations (e.g., philosophy of care and mission
statement), a review of the study's documents completed by participants (i.e., the Community Integration Questionnaire, the Family Participant Questionnaire, the pilot study comments/suggestions). All of these documents provided an opportunity to corroborate my data. As Glesne and Peshkin (1992) noted, "Documents corroborate your observations and interviews and thus make your findings more trustworthy." (p. 52)

**Recording Data**

Fieldnotes are "the written account of what the researcher hears, sees, experiences, and thinks in the course of collecting and reflecting on the data in a qualitative study" (Bogdan & Biklen, 1982, p. 107). Considered the primary recording tool of the qualitative researcher (Glesne & Peshkin, 1992), fieldnotes are the documents wherein rich data are recorded. In this study, fieldnotes simultaneously served to make sense of the data collection process and lend support to the data analysis process.

In the site selection phase, a log was created with the use of contact management software, which facilitated the documentation of all participant and key organizational contacts, telephone numbers, and schedules. Initial impressions, observations of all telephone conversations, concerns, and follow-up issues were carefully recorded (Field & Morse, 1985; Glesne & Peshkin, 1992). The contact management software facilitated my follow-up of issues that required attention (e.g., sample issues, commitments to participants to convene meetings, prompts regarding the receipt of pilot data, etc.) The log additionally served as a record of decisions and rationale related to methodology so as to establish an audit trail (Krefting, 1989).
The fieldnotes contained both objective-oriented recording and subjective-oriented recording (Field & Morse, 1985). Objective-oriented recordings enabled me to portray a profile of the participant (e.g., physical appearance, dress, mannerisms, styles of talking). They represented a forum in which I could paint a rich description of the setting/atmosphere, and reconstruct the dialogue, interactions, actions, and description of events. Additionally, the objectively-oriented fieldnotes documented learning that either corroborated or added to information in other documents (e.g., Family Participant Questionnaires). More importantly, the fieldnotes documented any concerns or other areas for consideration, the content of which would allow me to plan and deal with possible barriers that might present themselves throughout data collection. As much as possible, the fieldnotes were "descriptive and concretely analytic, without being interpretive" (Glesne & Peshkin, 1992, p.47)

The subjective-oriented recordings, in contrast, represented a license for my "non-neutrality" to emerge. Their purpose was to engage me in the process of becoming aware, knowledgeable, and insightful of any behaviours, as researcher, which threatened my neutrality. Hence, subjective-oriented recordings were a vehicle by which I might recognize my presence and personal journey throughout the research process. If I am conscious of how I may have been affecting and affected by the data, then I can improve my data collection processes (Field & Morse, 1985). Thus, the subjective-oriented recordings documented my awareness of subjective factors of being human, and all of the behaviours that affected the observation (i.e., biases, fatigue, distraction, intuitive thoughts, and emotional reactions). Recordings of what I heard, saw, and experienced
bound the observation, while reflections allowed for a greater depth and insight in the sense-making of the learning process, and thus represented a vehicle for sorting through emerging patterns. A copy of the Fieldnotes Guidelines is included in Appendix I.

The basis of all fieldnotes were my jottings throughout the course of interviews, which were made, in addition to the tape-recording of interviews. Moreover, such jottings encouraged me to listen attentively and, additionally, provided a back-up source of data in the event the tape recorder proved unreliable. Detailed fieldnotes were created as soon as possible following each of my interviews. These were usually originated immediately after the interview, and generally expanded upon, later that same evening. I tried to select quiet and private environments for these recollections, and kept a recorder at arm's length to be used while driving back from sites. Additional notes were taken and expanded upon following the opportunity to further reflect on the interview and key learning (Glesne & Peshkin, 1992). Such insights were incorporated into the fieldnotes. Off-record notes, consisting of a reconstruction of any conversations that occurred off-tape (i.e., before or after the recorder was turned on), additionally supplemented the fieldnotes. Finally, researcher comments notes were created while preparing transcripts; these reflected preliminary means of sense-making and provided preliminary ideas for theme identification, observations, contradictory or conflicting data, etc.

Data Analysis

In view of the qualitative design of this study, which presents greater complexities in the assessment of data (Kompf, 1991), the data collected from interviews with families
were descriptive in nature, and recorded on audiotape with the written informed consent of participants. I transcribed the audiotapes of all interviews verbatim. In keeping with the phenomenological and hermeneutics tradition, to which this study pays tribute, all pauses, voice inflections, and changes in tone were documented, as were all significant non-verbal behaviours (e.g., smiling) observed and noted at the time of interview.

All efforts were made to capture both verbal and non-verbal behaviour in a descriptive, rather than interpretive manner, so as to ensure as much neutrality as possible, and at the same time, maximize the likelihood of rich data emerging. Transcriptions were prepared as close in time to the date of the interview, usually within 48 hours, but sometimes as much as two weeks afterwards. In concert with these transcripts, the data additionally consisted of documentation relating to the CIQ and Family Participant Questionnaire, pilot data, contact management log, and detailed recording of all fieldnotes.

Although most audiotapes were of good quality with only occasional words inaudible, a few were of poorer quality, with frequent inaudible gaps of speech. In these cases, I listened to inaudible areas a minimum of five times prior to demarcating them as such with the symbol (.../???). Despite the fact that I was usually able to recall the nature of what was said, this was not indicated unless the audiotape could substantiate in some way my recollection. Because of time constraints, some transcriptions were created up to two weeks after the interview and, in those cases, the meanings of inaudible portions or subtleties in the interview were lost.

Procedural steps outlined by Colaizzi (1978) were used in this study for analysis of transcribed interview data. Prior to describing these procedural steps, however, it is
important to introduce the reader and researcher alike to the purpose of data analysis, on the one hand, and Colaizzi's (1978) phenomenological approach, on the other. Data analysis is "the process of systematically organizing what you have seen, heard, and read, so that you can make sense of what you have learned" (Glesne & Peshkin, 1992, p. 127). Such analysis is the "prelude to sensitive, comprehensive outcomes that make connections, identify patterns, and contribute to a greater understanding" (Bogden & Biklen, 1982, p.146). In working with the data, researchers create explanations, pose hypotheses, and develop theories that link their story with those of others. Accordingly, data analysis involves categorizing, synthesizing, searching for patterns, and interpreting the data gathered throughout data collection (Bogdan, 1972; Denzin, 1988; Field & Morse, 1985; Glesne & Peshkin, 1992; Lincoln & Guba, 1985).

Bogden and Biklen (1982) recommended that the novice qualitative researcher refrain from engaging in formal analysis until at least most of the data are gathered. I agreed wholeheartedly with their advice to defer formal analysis, mostly because it took most of my energy to merely keep up with the detailed and time-consuming collection and recording tasks! However, it is advisable to begin preliminary data analysis simultaneously with data collection (Glesne & Peshkin, 1992), since doing so allows researchers to focus and shape the study as it proceeds. I therefore followed the recommendation to consistently reflect on my data, work to organize them into rudimentary coding schemes, and try to discover what they had to tell me (Glesne & Peshkin, 1992). It is important to note that, inasmuch as it is advisable to weave the data collection and analysis process together (Glesne & Peshkin, 1992), the presentation of this discussion of data analysis, as
distinct from data collection and recording, is somewhat artificial, and is made more for ease of treatment in our logical-linear world, than as an accurate depiction of reality.

Sorting and analytic coding of data constituted the central procedure of the formal analysis process. I first read the data from each interview from beginning to end to achieve a sense of holism. I then re-read the data sets to identify and extract significant statements and phrases related to the issue of investigation, while unrelated information was also identified. I subsequently extracted, named, and documented major themes. Next, comments emerging from all informant interviews were organized under the named themes. Following a grouping and summary of common themes, I shared the final summary with participants for validation and to ensure that the summary accurately reflected their experience (Rothe, 1993). To draw more directly from the contextual data (i.e., fieldnotes, observations, reflections), I then shifted analysis to incorporate my perspectives as researcher.

If this approach to data analysis sounds like a purely logical, systematic analysis, allow me to say nothing could be further from the truth! For, given the tremendous and quite overwhelming amount of data typically generated by qualitative research approaches, I also felt I needed to explore the terrain in an intuitive way. I allowed myself to listen and trust my intuition, and gave myself permission to rely upon my inner self as a guide (St. James, 1995; Lather, 1988) to the overwhelming data bits. This approach to analysis proved to be not only productive, but playful, liberating, and freeing.

To aid me in the process of analysis, I also created data displays (i.e., tables and matrices). Data displays served to engage me in meaning-making of the data (Cole &
Hunt, 1994), and thus allowed me to identify the elements of my study (Glesne & Peshkin, 1992). I modified the data displays as I integrated the information more fully, and even drew diagrams with one-directional arrows to speculate on potential causal relationships. Following matrix construction, I would return to the data to conjecture on possible explanations. These strategies created the impetus for me to theorize about the social phenomenon under study (Glesne & Peshkin, 1992).

I then reconstructed, respectively, the themes of each data set, both individually, and holistically and, using the exact words of participants as much as possible, incorporated these into stories within a larger vignette. These formed the tangible products of the research: a rich and meaningful description of participants' perceptions of the quality of services received following the brain injury of their family members. Chapter 4 reports on the study's findings in the form of emergent themes.

Since meaning-making interpretation is the cornerstone of qualitative research (Cole & Hunt, 1994), it is appropriate to examine the underlying rationale for my use of a phenomenological approach to data analysis. The underlying assumption of phenomenology is that our preconceived meaning, or approach, of an undertaking regulates all of our involvements in it (Colaizzi, 1978; Lather, 1988). Writing against the positivist's claim to neutrality and objectivity (Lather, 1986a), Colaizzi (1978) defined objectivity as "fidelity to phenomena" (p.59). The phenomenologically-oriented researcher asks, "First, why am I involved with this phenomenon? How might the constituents of my uniquely personal personality condition my selection of this particular phenomenon to investigate? How might my personal inclinations and predispositions as to research value
influence or even bias how and what I investigate? What are the hidden gains that I might acquire in investigating it, and in investigating it in this way?" (Colaizzi, 1978, p.55)

The phenomenological research method is thus used to derive meaning by perceiving through the participant's reality. Phenomenology is "that kind of thinking which guides one back from theoretical abstraction to the reality of lived experience" (Field & Morse, 1985, p.27). Because it is a philosophy and a research approach that focuses on the meaning of the lived experience, the intention is to examine and describe phenomena as they appear in the experience of the individual. Hence, the phenomenological approach is characterized by an inductive derivation of human experience, for the purpose of discovering and describing the essence of meaning (Field & Morse, 1985).

One method of data analysis for phenomenological studies in psychology proposed by Colaizzi (1978) is protocol analysis. Procedural steps outlined by Colaizzi (1978) were used in this study for analysis of transcribed interview data (p.59-61). The first step of Colaizzi's method involved reading and re-reading transcripts of the interviews to acquire a feel for participants' descriptions. Secondly, significant phrases or sentences directly pertaining to the issue of investigation were highlighted in each transcript. To ensure focus on the specific research issues under investigation, a printout of the research questions was posted within eyesight distance for at-a-glance guidance. A statement was defined as significant if it described the participant's actual experience. Statements that were speculative or evaluative were not deemed significant. Comments that revealed descriptive, emotive, and/or interpretive information were all highlighted. Lists of extracted significant statements were created, during which time repetitions of similar
statements were eliminated.

The third step involved explaining the meaning of significant statements within each transcript. It involved a process of creative insight, a leaping from what participants said to what they actually meant. The formulated meanings were most often derived from those significant statements that described what occurred during service delivery, how participants felt about it, and what personal meanings, if any, had been assigned to the situation. During this step, I aimed as much as possible to "allow the data to speak for itself" (Colaizzi, 1978, p.59). A great deal of care was taken to ensure that the original protocols (i.e., data sets) were not severed from the formulated meanings derived. The goal was to discover and illuminate meanings hidden in the original protocols such that the formulated meanings remain connected with the data. Careful reading of each transcript, with consideration of statements preceding and following significant statements, secured both the parameters and the context of participants' descriptions.

The above steps were repeated for each data set, and the aggregate formulated meanings were organized into clusters of themes. In line with Colaizzi's fourth step, my aim was to allow for the emergence of themes that were common to all participants' experience. The clusters of themes were read and re-read. Theme formulation involved restating the groups of formulated meanings by summarizing them and transforming them into a statement that broadly captured the essence of the meanings. Consequently, themes were named and then followed by comprehensive descriptions to illustrate the complete structure of the experiences. Liberal inclusion of quotations in the descriptions allowed for illustration of how the themes emerged. Themes that were comprised of formulated
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meanings from all descriptions were identified as common themes and were included in the final exhaustive description.

As part of the fourth step, each theme was compared with the interview transcripts for validation. I looked for anything in the original protocols that was not accounted for in the clusters, and for anything in the clusters that was not implied in the original protocols. In her re-conceptualization of validity, Lather (1986), and other researchers (Colaizzi, 1978; Marshall & Rothman, 1989; Rothe, 1993), noted that it is essential that the research design seek counter-patterns as well as convergences, if data are to be credible. If a cluster of themes were not validated, I re-visited and re-examined the preceding procedures. Discrepancies were noted among and/or between the various clusters. Special care was taken, during this stage, to avoid ignoring data or themes which do not fit.

In the fifth step, the results of the analysis were integrated into an "exhaustive description" (Colaizzi, 1978, p.60) of the issue of investigation. An effort was made to formulate this exhaustive description in a concise and brief statement of no more than a few paragraphs. Formulated meanings that were deemed to be unique to the experience of one or two participants (rather than all participants) were not incorporated within the exhaustive description.

Finally, the last validating step in the method involved reflecting upon the identified synthesis of formulated meanings and exhaustive description of common themes back to participants, in the hopes of validating the "truth" of the findings. Participants were asked "how do my descriptive results compare with your experiences? What aspects of your
experience or of your existence have I omitted?" (Colaizzi, 1978, p.62). Any relevant new data that emerged from these member checks (Lincoln & Guba, 1985) were thus incorporated into the final product of the research.

The individual member checks helped to validate the findings obtained from both interviews. The member checks furthermore helped to ensure an accurate interpretation of the emergent themes. As an additional measure of precaution, my thesis committee had previously reviewed three interview transcripts and made recommendations for the validation of my interview technique. Additionally, my thesis committee reviewed and approved two randomly selected analyses of the data to ensure that no subjective bias on the my part, as researcher, was introduced in the research process. Moreover, an unbiased graduate candidate with no vested interest in the outcome was asked to conduct an independent critical analysis of the data. As described earlier, the candidate reviewed two random selections of the analysis, and performed independent and unbiased critical analysis according to the stipulations of Colaizzi's method of protocol analysis. Although the candidate's naming of themes differed slightly from my selections, the essence of the analysis and the meanings derived from participants' words were very similar.

Finally, the process of validation occurred as a corollary of Colaizzi's protocol analysis. All significant statements were read over and validated against the transcripts from which they were extracted. Another validation step involved the extraction of significant statements and corresponding formulated meanings to ensure that they were clear and accurate reflections of the subsumed significant statements. The results of this validation with my supervisor were used to correct and enhance the analysis of the
remaining six transcripts. With these various measures taken, I was satisfied in the knowledge that objective analysis had been conducted, and, therefore, confidence in the research findings was indeed warranted.

**Methodological Rigor**

Comparability is the clear delineation of characteristics of the sample studied so that their similarities and differences can be identified (LeComte & Goetz, 1982). I designed a detailed table for the purpose of comparing the demographic characteristics of participants (Table 1). Developing a logic that will solidly defend a research study entails two domains: (i) responding to criteria for the soundness of the project, and (ii) demonstrating the usefulness of the proposed work to the conceptual framework and research questions (Marshall & Rossman, 1989).

In lieu of quantitative standards of validity and reliability, I used measures of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985) in this study to ensure a high degree of rigor. Lincoln and Guba, 1985, proposed that these four alternative constructs more accurately reflect the assumptions of the qualitative research paradigm.

**Credibility**

The first criterion of rigor, credibility, asks researchers to demonstrate that "the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described" (Lincoln & Guba, 1985, p.296). "Validity or truth value in
Qualitative research is evaluated using the criterion of credibility" (Lincoln & Guba, 1985, p.294). A study is credible if participants involved in the research read the descriptions of the phenomenon and immediately recognize the experience as their own.

Insofar as the researcher is the instrument for data collection and analysis in qualitative research, credibility is threatened because personal biases may influence either process (Lincoln & Guba, 1985). This may particularly have been so in my case: Being a family member of a loved one who sustained a brain injury, myself, I might have been more inclined to identify with caregivers, and introduce subjective bias into the research process.

The use of a structured, open-ended interview guide, however, (Appendix J) minimized the introduction of bias during data collection, as did my concerted effort to focus and attend on truly hearing the informant's words, as preparation for the interview. Credibility would have been threatened had leading questions been asked which inaccurately reflected what I intended to study (Kvale, 1983). Instead, I tried to ensure that the questions in the Family Interview Guide were neither leading, nor value-laden. By thoroughly pilot testing both instruments, I confirmed both content and face validity.

Other strategies utilized to control instrument bias included the tape-recording of interviews and transcribing them verbatim. In doing so, I was able to interpret participants' experience using their own words. Another strategy to control instrument bias included selection of the unfamiliar (i.e., settings and people) for data collection (Glesne & Peshkin, 1992). Because I chose sites in which I had never practiced, and participants I had never counselled, the likelihood of subjective bias was minimized.
Trustworthiness was also enhanced by the amount of time spent at the research site, actual time spent interviewing, and time invested in building sound relationships with respondents -- all of which contribute to trustworthy data (Glesne & Peshkin, 1992). Careful self-examination conducted through the analytic logs and fieldnotes, as well as effective self-monitoring and my continual alertness to my own biases and subjectivity practiced throughout the study, also assisted me in producing trustworthy interpretations. Finally, my acknowledgements of the study's limitations contributed to the trustworthiness of my data (Glesne & Peshkin, 1992).

**Transferability**

The second criterion of rigor that Lincoln & Guba (1985) proposed, as the criterion against which the applicability of qualitative research be evaluated, is transferability, (i.e., generalizability to other settings). The burden of demonstrating the applicability of one set of findings to another context rests more with the investigator who would generalize than with the original investigator.

Triangulating multiple sources of data can enhance a study's generalizability (Field & Morse, 1985; Glesne & Peshkin, 1992; Lincoln & Guba, 1985). In triangulation, more than one source of data is brought to bear on a single point to corroborate the issue of investigation. Designing a study in which multiple cases are used, multiple informants, or more than one data-gathering technique can greatly strengthen the study's usefulness for other settings (Glesne & Peshkin, 1992). Documents that corroborate observations and interviews are not only helpful with the generalizability of the study's results, but also in
making findings more trustworthy (Glesne & Peshkin, 1992).

**Dependability**

In the third criterion of rigour, dependability, the researcher attempts to account for changing conditions in the phenomenon chosen for study, as well as changes in the design created by increasingly refined understanding of the setting (Lincoln & Guba, 1985, p. 147). Because dependability is the criterion of rigor that relates to the consistency of qualitative findings, it is proposed by Lincoln and Guba as a substitute to the quantitative measure of reliability. "Reliability or consistency in qualitative research is evaluated using the criterion of dependability" (Lincoln & Guba, 1985, p.299). "Dependability is demonstrated when other readers can follow the thinking, decisions, and methods used by the original investigator to arrive at the same or comparable conclusions" (Lincoln & Guba, 1985, p.318; Sandelowski, 1986).

To this end, all stages of the research process are described in detail. I have reported all decisions involved in allowing for the transformation of raw data to thematical schema, leaving a clear decision audit trail concerning the study from its inception to its end. My thesis committee reviewed my initial groupings of behaviours, as did an independent and unbiased graduate candidate. All agreed that the critical analysis procedures conducted accurately depicted the data.
Confirmability

The final criterion of rigour, confirmability, captures the concept of objectivity in quantitative parlance (Lather, 1986a, 1988). By stressing whether the findings of the study could be confirmed by another, Lincoln and Guba (1985) removed evaluation from some inherent characteristics of the researcher, and placed it squarely on the data themselves (p.147). Data that are as free from bias as possible are achieved as the criteria of credibility, transferability, and dependability are met. These tests of rigor ensured that the exhaustive description (Colaizzi, 1978) which emerged in this study was grounded in the data from which it was derived.

Limitations of the Study

If demonstrating the trustworthiness of the data is the qualitative researcher's ethical obligation and responsibility, part of demonstrating trustworthiness is to realize the limitations of the research study (Glesne & Peshkin, 1992). In this vein, it is important to note that the results of this study are not generalizable due to the small and select convenience sample of eight participants. However, the sample characteristics were described in detail to allow other researchers to make decisions as to the representativeness of this sample vis-a-vis their own research (MacMillan & Schumacher, 1989).

A significant limitation, as is commonly the case with qualitative research, consists of the subjectivity inherent in the researcher as an instrument of data collection. A detailed discussion of the inherent dangers of subjective bias in qualitative research was included in the section entitled Researchers' Role, Relationships, and Experience.
Moreover, the conditions surrounding access of participants (i.e., sample selection, participants' eligibility for inclusion, and convenience of location to research site) constituted additional limitations. For example, access difficulties in this study involved unique challenges in locating research sites that could adequately support my sample characteristics. In a related vein, access difficulties took the form of participants' ineligibility for inclusion in the research study. Only 43% of the total pool of recruits met sample characteristics, and were thus qualified for inclusion. Finally, my own willingness to travel to research sites that were convenient posed as additional constraints to access. All of these factors imposed limitations upon this research study.

Furthermore, it is plausible that the research study may have been overly ambitious in terms of the number of questions posed to participants. The onerous time commitment, intensity of questioning, and sensitivity of information may have had adverse effects upon participants, and thus inadvertently affected the quality of their responses.

Yet another limitation deals with the phenomenological approach. Although this qualitative method was effective in eliciting descriptions of quality of service and levels of satisfaction, it was frequently difficult for many participants to isolate the phenomenon of interest for description. In many instances, various life experiences were so enmeshed that it was difficult for participants to describe one in isolation of another experience.

Additionally, a methodological limitation of the study concerns its reliance on self-reported information, which was collected from the families of persons with brain injury. Self-reported information may be biased for a variety of reasons. For example, responses may be affected by family members' emotional distress, animosities towards the head-
injured person, or a tendency to exaggerate or minimize complaints (Stiles Camplair, et al., 1990).

Finally, another limitation concerns the use of the CIQ as a benchmark for determining inclusion. That the instrument's scores do not reflect a particular category of mild, moderate, and severe might have imposed limitations upon the comparability of data. A discussion of the instrument's history and its inherent limitations is initiated in the fourth chapter on Findings.

Summary

This qualitative study explored the perceptions of families of the brain-injured in regards to the degree of satisfaction with the quality of service received. Additionally, the study expounded recommendations as to how to improve upon the overall quality of health care to the target population. A total of eight informants consented to participate in this study, all of whom were recruited from diverse organizations specialized in traumatic brain injury rehabilitation. Varied methods of data collection were selected to facilitate the process of understanding the perceptions of families of the brain-injured vis-a-vis their satisfaction with services received. A series of orientation and semi-structured interviews were central, but methods also included observation, document review, telephone conversations, and fieldnotes. Although some strategies of analysis were employed throughout the time in the field, the main data analysis process followed data collection. Out of the data sorting and coding recommended by procedural steps outlined by Colaizzi's (1978) method of protocol analysis, there emerged a representation of
participants' stories/vignettes. These are to be presented in the following chapter.

Qualitative research criteria of rigor were discussed in detail, with substantiating and supporting information offered as to how a high degree of rigor for this study was ensured.
CHAPTER FOUR: FINDINGS

Introduction

My intent in this research study was to foster an understanding of families of the brain-injured's perceptions concerning the degree of satisfaction with the quality of service received. Additionally, the study aimed to identify whether or not there are any gaps in service provision, and solicit recommendations as to how to improve upon the overall quality of health care to the target population. In this chapter, I will report the findings of this exploration.

This chapter has been organized according to three main sections, all of which inform upon the research questions described in detail in the introductory chapter. The first section presents the demographic data derived from information obtained from the Family Participant Questionnaires. The second section centres upon the use and inherent limitations of the Community Integration Questionnaire as a decision-making/screening tool vis-a-vis inclusion criteria. In light of the instrument's numerous limitations, the thesis committee and I decided that a discussion of the discrepancies in scores that arose between the two dual-family caregiver groups studied would contribute little to the overall discussion of results. As such, it was deemed unnecessary to report upon these particular research results. The third and final section treats the subject of emergent themes which evolved as a result of the private interviews with participants.
Demographics of Sample/Family Participant Questionnaire Findings

Derived from information obtained from the Family Participant Questionnaires, the following findings shed light upon: (i) participants' demographic data; (ii) the history of the family (i.e., family membership, the nature of family relationships, pre- and post-injury status); (iii) details of the injury; and, (iv) type, use, and need of family services utilized.

The following information is summarized in Tables 1 and 2, respectively.

In total, the female-dominant sample consisted of eight participants, seven of whom were female (87.5%) and one of whom was male (12.5%). The age of informants ranged from 24 to 57 years of age, with a mean of 45.4 years. While six of eight participants in the total sample were married (75%), one was single (12.5%), and another divorced (12.5%). As far as their gross annual family income was concerned, three participants classified themselves in the $91,000+ category (37.5%), another three participants reported earnings in the range of $51,000-$70,000 (37.5%), and yet another two participants reported earnings in the range of $10,000-$30,000 (25%).

With respect to the level of education completed to date, the sample was again quite stratified, with three participants having graduated from high school (37.5%), another having attended college (12.5%), another having completed her undergraduate degree (12.5%), and yet another three having attained a graduate degree/professional designation (37.5%).

At the time of study, five participants were employed on a full-time basis (62.5%). Another participant, a full-time homemaker, stated she was unemployed outside of her home (12.5%). Another woman was employed on a part-time basis (12.5%), while the
spouse of a brain-injured individual was on long-term leave due to health reasons (12.5%).

Unsurprisingly, this leave was believed to be precipitated by her spouse's brain trauma and the resultant family stress.
**Table 1**  
**Frequency Counts of Demographic Variables**

<table>
<thead>
<tr>
<th>SAMPLE CHARACTERISTICS</th>
<th>FREQUENCY (N = 8)</th>
<th>RELATIVE FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
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<tr>
<td>16-25</td>
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<tr>
<td>26-35</td>
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<tr>
<td>36-45</td>
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<tr>
<td>46-55</td>
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<td>0.50</td>
</tr>
<tr>
<td>56-65</td>
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<td>0.13</td>
</tr>
<tr>
<td>65+</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>0.88</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
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<td></td>
</tr>
<tr>
<td>Single</td>
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<tr>
<td>Married</td>
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<td>0.75</td>
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<tr>
<td>Separated</td>
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<td>0.00</td>
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<td>Divorced</td>
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<td>0.13</td>
</tr>
<tr>
<td>Widowed</td>
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<td>0.00</td>
</tr>
<tr>
<td><strong>Education</strong></td>
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<td></td>
</tr>
<tr>
<td>Elementary</td>
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<td>0.00</td>
</tr>
<tr>
<td>Junior High School</td>
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<td>0.00</td>
</tr>
<tr>
<td>High School</td>
<td>3</td>
<td>0.38</td>
</tr>
<tr>
<td>Post Secondary (college/workshop)</td>
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<td>0.13</td>
</tr>
<tr>
<td>University (undergraduate)</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td>University (graduate/professional)</td>
<td>3</td>
<td>0.00</td>
</tr>
<tr>
<td><strong>Employment/Work Life</strong></td>
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<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>5</td>
<td>0.63</td>
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<tr>
<td>Part-time</td>
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<tr>
<td>Student</td>
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<td>0.00</td>
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<tr>
<td>Homemaker</td>
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</tr>
<tr>
<td>Unemployed/Leave of Absence</td>
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</tr>
<tr>
<td>Retired</td>
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<td>0.00</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
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</tr>
<tr>
<td>Bookkeeper</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Building Superintendent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Business Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chartered Accountant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counsellor/Therapist</td>
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<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life Insurance Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teacher</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gross Annual Family Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$10,000 - $30,000</td>
<td>2</td>
<td>0.25</td>
</tr>
<tr>
<td>$31,000 - $50,000</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>$51,000 - $70,000</td>
<td>3</td>
<td>0.38</td>
</tr>
<tr>
<td>$71,000 - $90,000</td>
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<td>0.00</td>
</tr>
<tr>
<td>$91,000 +</td>
<td>3</td>
<td>0.38</td>
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</table>
## Table 2
**Frequency Counts of Sample Characteristics**

<table>
<thead>
<tr>
<th>SAMPLE CHARACTERISTICS</th>
<th>FREQUENCY</th>
<th>RELATIVE FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type, use, &amp; need of family service utilized</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>INDIVIDUAL COUNSELLING:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Case Worker</td>
<td>4</td>
<td>0.50</td>
</tr>
<tr>
<td>- Hospitals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Physician</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Psychiatrist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Psychologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Rehabilitation firms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Social Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FAMILY COUNSELLING:</strong></td>
<td>4</td>
<td>0.50</td>
</tr>
<tr>
<td>- Caseworker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Hospitals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Marriage Counselling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Occupational therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Private rehab firms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Psychologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Social Worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FAMILY SUPPORT GROUP:</strong></td>
<td>3</td>
<td>0.38</td>
</tr>
<tr>
<td>- Rehabilitation firm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Brain injury support organization</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>EDUCATION VIA HEALTH CARE FACILITIES:</strong></td>
<td>4</td>
<td>0.50</td>
</tr>
<tr>
<td>- Hospitals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Rehabilitation Centres</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>EDUCATION THROUGH MEMBERSHIP:</strong></td>
<td>6</td>
<td>0.75</td>
</tr>
<tr>
<td>- Brain injury support organizations</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>OTHER EDUCATION:</strong></td>
<td>4</td>
<td>0.50</td>
</tr>
<tr>
<td>- Direct employment and training in rehabilitation field</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Review of head injury literature</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Voluntarism in rehab field</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>OTHER:</strong></td>
<td>2</td>
<td>0.25</td>
</tr>
<tr>
<td>- Talks with psychologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Informal supports, (ie., friends, family, religious affiliations, neighbors, etc.)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Table continues)
Table 2 (continued)
Frequency Counts of Sample Characteristics

<table>
<thead>
<tr>
<th>SAMPLE CHARACTERISTICS</th>
<th>FREQUENCY (N = 8)</th>
<th>RELATIVE FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Constitution of Family Membership</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Traditional (Nuclear family: both parents &amp; their children)</td>
<td>7</td>
<td>0.88</td>
</tr>
<tr>
<td>Non-traditional (Single parent)</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td><strong>Kinship of Caregiver in relation to injured individual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent of injured child</td>
<td>4</td>
<td>0.50</td>
</tr>
<tr>
<td>Spouse of injured individual</td>
<td>3</td>
<td>0.38</td>
</tr>
<tr>
<td>Sibling of injured individual</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td>Adult Child of injured individual</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td><strong>Nature of Family Relationships</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRE-INJURY:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very close</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td>Somewhat close</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td>POST-INJURY:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Even closer</td>
<td>3</td>
<td>0.38</td>
</tr>
<tr>
<td>Less close</td>
<td>2</td>
<td>0.25</td>
</tr>
<tr>
<td>No change</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td><strong>Living Arrangements of primary caregiver in relation to brain-injured individual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain-injured individual lives with caregiver</td>
<td>7</td>
<td>0.88</td>
</tr>
<tr>
<td>Brain-injured individual lives independently</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td><strong>Details of Injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Driver in a motor vehicle accident</td>
<td>2</td>
<td>0.25</td>
</tr>
<tr>
<td>Passenger in a motor vehicle accident</td>
<td>2</td>
<td>0.25</td>
</tr>
<tr>
<td>Motorcycle accident</td>
<td>2</td>
<td>0.25</td>
</tr>
<tr>
<td>Cyclist struck by an automobile</td>
<td>1</td>
<td>0.13</td>
</tr>
<tr>
<td>Work-related accident</td>
<td>1</td>
<td>0.13</td>
</tr>
</tbody>
</table>

*Discrepancies in totals are due to rounding to the tenth decimal.*
Of participants performing white collar work, occupations ranged from business management, chartered accounting, management in the life insurance industry, teaching, public health nursing/education/bookkeeping, and counselling/therapy. Of those performing blue collar work, participants were employed as a building superintendent and cashier.

In addition to these demographic data yielded from the Family Participant Questionnaires, information pertaining to the history of the family also emerged. Such information consisted principally of details relating to family membership and the nature of family relationships, both pre- and post-injury status. In terms of the constitution of family membership, most families (87.5%) consisted of both parents and their children. One of the eight families in the sample (12.5%) consisted of a single mother of three adult children.

All participants differed vis-a-vis their role/relationship to the brain-injured family member. With respect to the kinship to caregiver variable, four primary caregivers who participated in this research study were parents of their injured children (50%). In another three instances, primary caregivers consisted of spouses of brain-injured individuals (37.5%). Finally, one participant was a sibling of her injured sister (12.5%).

Of the traditional families, most had only one primary caregiver participating in the study, with the exception of two families. Amongst the exceptional cases, where only one person participated in the study as primary caregiver, one family unit consisted of two parents (both of whom participated as primary caregivers), their brain-injured son, and two other adult daughters. The mean age of the adult children was 26. In another family
unit with two primary caregivers participating in the study, the primary caregivers were a mother and daughter dyad. Their family consisted of their mildly brain-injured spouse/father, severely brain-injured daughter/sister, and two daughters/siblings, both of whom were living independently. The mean age of the four adult children of this family unit was 21.

Amongst the remaining families with only one primary caregiver participating in the study was a family consisting of the primary caregiver, her injured spouse, and their two adopted adult children, whose mean age was 22 years. In yet another family unit, there were four persons consisting of the primary caregiver, her brain-injured spouse, and their two adult twin children aged 26 years. Finally, in another instance, the primary caregiver was a female spouse, her brain-injured spouse, and their son of five months.

In yet another family unit, the primary caregiver was a single mother. Her family unit consisted of her injured son living independently, and two other adult children whose mean age was 20.7.

Another studied variable of interest concerns participants' perceptions of family relationships in relation to their pre- and post-injury status. Participants were asked to qualify their family relationships prior to the traumatic event on the Family Participant Questionnaire. To assist them with their response, a sliding scale of choices ranging from very close, somewhat close, not close, distant, to indifferent, was provided. Seven of the eight participants responded that they viewed their family relationships as very close prior to the traumatic event (75%). Within this grouping, one woman offered to describe her relationship with her injured spouse as very close; however, indifferent with her adult
sons (12.5%). Yet another woman characterised her family relationships as somewhat close (12.5%).

To obtain a sense of the effect of brain trauma upon family relationships, participants were also asked how their family relationships changed as a result of brain trauma. When requested to specify the appropriate answer, they were offered one of four choices, including: my relationships with my family became more distant than before the trauma; even closer; less close; and no change. While three participants (37.5%) reported that their family relationships were even closer, two others reported they were less close (25%), and yet another two reported there was no change (25%). Within the no change response category, one participant offered to break down her family relationships more specifically, indicating that she became closer with her injured spouse, while withdrawing from her son. There were no reported changes with this participant's relationship with her adopted daughter. Overall, although the information obtained from the history of the family proved interesting and somewhat informative, there are numerous limitations imposed upon this particular aspect of data collection.

Another variable considered worthy of investigation was the living arrangements of the primary caregiver in relation to the brain-injured individual. Seven of the eight individuals in the sample reported that their injured family member lived within their family unit (87.5%), while the remaining participant (12.5%) stated that her injured son lived independently.

As far as the details of injury are concerned, the lower and upper range date of family members' injury was between June 1990 and October 1993. The median onset
since injury is approx. 3.3 years, which falls within the purview of the original inclusion criteria for participation of 18 months to 4 years post-injury. Amongst the group of brain-injured family members, two individuals (25%) were drivers of an automobile involved in a motor vehicle accident while another two (25%) were passengers. Other individuals were injured as a result of a motorcycle accident (12.5%), a cycling accident where the bicyclist was struck by an automobile (12.5%), and a work-related accident (12.5%).

Finally, the Family Participant Questionnaire informed the researcher and readers alike as to participants' type, use, and need of family service utilized following brain trauma. In this section, informants were requested to enlist the types of services they or their families utilized to help them cope with the traumatic brain injury of their family member. Given a choice of individual counselling, family counselling, family support groups, education via hospitals or rehabilitation centres, education through organizational membership, education via other means (to be specified), and miscellaneous/other (to be specified), participants were asked to circle all of the appropriate answers, and indicate the location where they had received such service. Participants were additionally requested to specify whether they or their family actively sought the service(s), or had the services offered to them by the service provider. Interestingly, of all participants in the sample, no one chose to identify himself/herself as either an aggressive or passive seeker of service, as originally requested. I will speculate as to the reasons for their lack of divulgence, and raise the question as to the factors related to aggressive pursuit of service and its relationship to satisfaction with service provision, in the final Chapter 5 on Discussion/Conclusions.
In general, however, four female participants pursued individual counselling (50%) obtained predominantly from social workers at the various organizational sites consulted. In one family's circumstance, each individual family member individually consulted with a psychologist, with the exception of the injured spouse. The primary caregiver in this particular family unit additionally consulted with a psychiatrist for her Traumatic Stress Disorder (TSD) syndrome, allegedly triggered by the onset of trauma. In other cases, participants reported obtaining individual counselling via various hospitals. Another reported receiving individual counselling from her family physician, as well as her spouse's rehabilitation firms.

Family counselling was also delivered to four of the eight participants (50%). Service providers of family counselling services were comprised of social workers at various hospitals and rehabilitation centres, and a psychologist at another organizational site. Marriage counselling was sought in another instance to manage an injured spouse's verbal abuse that resulted as a corollary of brain trauma.

Only two participants (25%) listed family support groups as their treatment choice. In these cases where such service was sought, it was obtained via a rehabilitation centre and via various brain injury information and support services (including a monthly spousal support group).

Other services identified by families were provision of education via hospitals or rehabilitation centres. Under this category, four of eight participants (50%) indicated they had received education from family education evenings at the hospital, and rehabilitation centres. Five of eight people (62.5%) stated they received education through enlisting
membership in various organizations. Interestingly, within this section, one outspoken participant commented, "There seems to be a large void in the area of education regarding brain injury, its impact, and sequelae on the brain injured individual, as well as the family. I wanted more information and was always told that what I wanted was not available."

Within the other education category, one participant (12.5%) indicated that she was informed by reviewing articles on head injury-related topics, while another (12.5%) identified her direct employment and training in the rehabilitation field as a means of education.

In the final other category, five participants (62.5%) offered to disclose other services utilized as a means of coping with the family stress resulting from brain trauma. One individual listed discussion with a psychologist regarding the repercussions of brain injury upon her injured family member and herself. Another cited reading material as a useful service. Yet three others deemed informal supports invaluable, as evidenced in their mention of the use of the "church," "family physician-turned-friend," "neighbour", "friends," or "friends/family." The interesting inclusion of informal support systems, in addition to, and sometimes in lieu of, the professional gamut of service, is discussed in further detail under the section on emergent themes of this chapter.

In summary of the two sections presenting demographic data and history of family, injury, as well as the use, type, and need of family service, it is clear that there were significant variations in the data. Surprisingly, many participants responded to the question of perceptions regarding quality of service by almost exclusively focussing upon the service offered to their brain-injured family member. It is arguable, however, whether
or not such an emphasis constitutes family service. A few others focused more single-mindedly on themselves or other family members as recipients of family service. Yet others responded using some combination of the two. Similar substantive differences in the data existed along a continuum of aggressive versus passive seekers of services, with noted differences between those who aggressively sought service and those who were mere recipients of services. An elaborate discussion of these and other substantive differences is contained in Chapter 5.

The Community Integration Questionnaire (CIQ) Findings

To gather data on the degree of social displacement/level of community integration and ensure appropriate comparability of data, participants completed the Community Integration Questionnaire (Willer et al., 1993a; Willer et al., 1994). The CIQ instrument is designed to assess home integration, social integration, and productivity in persons with traumatic brain injury. Willer's (1994) application guidelines stipulated that, in the ideal, the brain-injured individual should complete the questionnaire to obtain a measurement of community integration. For the sake of expediency, however, family member participants were, instead, requested to complete the form in proxy during the study's initial orientation interviews. This departure from habitual norms is nonetheless considered to be an acceptable alternative.

The three subscales of the CIQ consist of a total of 15 questions. The overall score, which represents a summation of the scores from individual questions, ranges from 0 to 29. A higher score indicates greater integration while a lower score reflects less
integration.

Overall, analysis of the CIQ results revealed that there are tremendous challenges in the utilization of the CIQ instrument as a screening device. Because it is not intended as an assessment tool, the complexities of its usage as a screening device are numerous. For one thing, actual scores did not correspond to a diagnostic category of mild, moderate, or severe level of social displacement. That there is no system of classification of scores poses unique challenges with decision-making vis-a-vis inclusion criteria. Because a particular score cannot be categorized into any given category, one might argue that decision making for inclusion becomes arbitrary and subject to the individual discretion, vicissitudes, or whims of the investigator.

A more serious but related difficulty concerns the inherent risk that comparability of data may be threatened by a lack of categorization in levels of social displacement. If the instrument is utilized as a screening device, is it not possible that comparability of data is jeopardized if the quantitative measurement it yields cannot qualify levels of social displacement? By the same line of reasoning, if the comparability of data is questionable, then does this not raise question as to the meaningfulness of the study's results?

Usage is also rendered difficult by family members' completion of the questionnaire in proxy. The CIQ is normally completed by the brain-injured individual being assessed (Willer et al., 1994). In cases where the individual is unable to complete the questionnaire due to communication deficits, memory impairment, or cognitive deficits, a person familiar with the injured individual may complete the assessment. Moreover, it is unknown whether the heterogeneous perceptions of the dual-family caregivers are an accurate
reflection of reality or a mere consequence of confusion in which the participant has inadvertently forgotten the perspective from which he/she has been instructed to respond to the questionnaire items. This evidently carries tremendous implications in terms of the response categories offered. From this particular proxy perspective, the response choice *yourself* in this case refers to the brain-injured individual, not the caregiver. Similarly, *someone else* designates a range of possibilities, including the caregivers, friends, neighbours, etc. Requesting that the injured individual complete the questionnaire as a means of corroborating family members' perception will not likely absolve us of the dilemma. Presumably, depending on the nature of the injury, there may be questions as to the injured member's credibility.

Another difficulty in its usage for screening purposes concerns the fact that categories are not exhaustive and do not represent all of the possible range of all participants' experience, the result being that it is difficult to classify where people fit along the continuum. In the productivity scale, for example, there are scores granted for an injured individual's participation in school, employment, or volunteer activities. Scores vary according to various levels of participation, as defined by either part-time or full-time involvement in the case of school or employment, or the number of days per month devoted to voluntarism. Difficulties in scoring arise when no guidelines are provided as to how would one score injured individuals who do not fall within this specified realm, (i.e., homemakers; children who are too young to be employed; adults working without remuneration, etc.) Again, scoring in these instances appears to be contingent upon the researcher's individual judgement/discretion.
Additionally, the instrument does not allow us to determine whether the injured individual is prevented from integrating because of his/her disabilities, or because of other factors in the environment (i.e., familial overprotectiveness, patronizing, or simply impatience). Hence, the family environment or constellation becomes in itself an important vehicle by which independence may be supported or thwarted, and is therefore highly relevant to integration outcomes.

According to Willer et al. (1993a), another major concern with the CIQ instrument is that only behavioral states are described. Feeling states, such as the individual's level of satisfaction with integration, are not assessed. Similarly, the instrument does not assess the degree to which the individual chooses to be integrated. Another difficulty with the CIQ, which would exist with any measure of rehabilitation outcome, rests upon the reason for the lack of integration. As mentioned earlier, the instrument does not allow us to determine whether the individual is prevented from integrating because of his/her disabilities or because of other factors in the environment.

Many of these limitations are a function, directly or indirectly, of the fact that the validity of the CIQ is yet to be clearly established and therefore is not yet up to the standards proposed for program evaluation instruments (Johnston, Keith, & Hinderer, 1993). Because of these types of limitations, the CIQ's usefulness as a quantitative index of community integration is questionable. Additional information is needed concerning its utility as a screening device for the guidance of research studies. Until such information is available, it is perhaps preferable for researchers considering replicating the study's results or conducting similar lines of research to utilize the Glasgow Coma Scale as a more
trustworthy measure of level of severity.

**Family Interview Findings**

Through analysis of the eight interview transcripts, all significant statements extracted in each private interview were translated into formulated meanings, the aggregate of which represents emergent themes. The final stages of analysis revealed seven central themes common to all participants' experiences, all of which in turn include several strands of interconnected sub-themes. These major thematic clusters include:

(i) education; (ii) control; (iii) practitioners' disposition and character traits; (iv) practitioners' qualifications, professionalism, and competency issues; (v) lack of family-focused service; (vi) the need for professional and non-professional support as a means of facilitating adjustment to trauma; and, (vii) systemic issues.

As readers might expect, grouping formulated meanings and allowing for the emergence of themes demands considerable contemplation, time, and patience from the researcher. I focused upon the formulated meanings until clarity of thematic representation was achieved. While some formulated meanings were not immediately recognizable as components of a theme, careful study of the meaning statements within the context of their expression allowed for recognition of how the meanings either served to reinforce a particular theme or to expand upon one of the many dimensions of a theme.

Major thematic clusters are defined by a representation of a minimum of 60% unanimity in the sample population studied. Although Colaizzi's (1978) method of protocol analysis clearly recommended that no formulated meaning be discarded, (but
rather subsumed under one or more theme[s], or embraced within a miscellaneous category), this advice could not be heeded to by virtue of the tremendous volume of data generated by the research questions. Accordingly, descriptions with less than 60% representation from the sample were discarded from the presentation of findings. The criterion of 60% was selected because it was considered an appropriate benchmark of unanimity. This means that out of eight participants, at least five people described similar experiences. Additionally, by virtue of the sheer repetition of statements made, I deduced that the major thematic clusters identified were of greatest significance for participants.

It is important to note that though thematic clusters represent at least 60% agreement in the sample studied, there was nonetheless conflicting results and differences in opinion. Participants, for example, may identify that education is important to them; however, there may be great discrepancies in how they would like to see educational programs being implemented, or which facets of educational programs require urgent attention. Similarly, all may feel generally satisfied about the availability of practitioners; however, some may still suggest that greater access is warranted when they are out-of-town or otherwise distant from service locations.

While the seven common themes constitute the essential structure of the description of families' perceptions, concerning their degree of satisfaction with the quality of service received, there were also other emergent themes which represent atypical experiences. Atypical experiences with less than 60% representation include: (i) practitioners' degree of responsiveness, attentiveness to family needs, and willingness to customize/personalize family's needs, and; (ii) opportunity for client participation in care
and decision making/degree of client involvement in process. Because each atypical experience did not satisfy the minimum of 60% representation criterion, they were discarded. The formulated meanings that reflected these experiences were not present in 60% of descriptions, and were not identified as common; as such, they did not constitute a theme per se.

In so far as the naming of themes is concerned, the derivation of the theme name occurred in one of two ways. The name was either suggested directly from the participant's own words. Alternatively, it was suggested by my inference of the intended meaning of a cluster of similar descriptions. In such instances, several measures of precaution were taken to guard against unjustified creative leaps in data analysis. These were clearly outlined in Colaizzi's method of protocol analysis in the Data Analysis section of Chapter three.

It is of paramount importance to emphasize at the outset that because all findings reported pertain exclusively to the specific sample studied, they are not a reflection of the viewpoints of all primary caregivers of all brain-injured individuals in the general population, nor are they necessarily a reflection of all practitioners of rehabilitative service. The findings of any research study pertain exclusively to the unique parameters of the sample characteristics studied. Further research using larger samples would need to establish whether or not the patterns identified in this study are reflective of "reality" as a whole.

It is equally important to bear in mind at the outset that although the central focus of this study was the community re-entry phase, participants tended to focus their
conversations on the acute and rehabilitation phases. In general, the three phases of rehabilitation which were the subject of participants' descriptions were highly interwoven and interconnected, resulting in difficulties triaging the data. To respect participants' freedom of choice in responding to all open-ended research questions posed and at the same time pay homage to the research questions -- an attempt was made to give greater prominence to data pertaining to the community re-entry phase, while minimizing the weight of the acute and rehabilitation phases (wherever this was possible and warranted). For this reason, data relating to all three phases of the rehabilitation process have been incorporated in the presentation of findings.

Prior to presenting the findings on emergent themes, I also want to underscore the fact that all themes are interrelated and interconnected in some way(s), despite the fact that they are presented as separate and distinct from one another. For ease of presentation, themes will be presented in a logico-linear way, and all attempts will be made to establish the interrelationships as best as possible. The presentation of families' experiences has thus been organized theme by theme. Detailed descriptions of themes are provided, with illustrative quotations used throughout the presentation to serve to illuminate the decision trail from significant statements to thematic representation. All participants have been represented equally in terms of the quotations selected for inclusion. To respect norms for confidentiality and anonymity, all personal names, names of participating organizations, and references to practitioner type have been concealed and are represented by the symbol [*].
Emergent Themes

Education

The first theme, which weaves across all participating families in this study, is an overwhelmingly consistent emphasis on the pivotal role of education. Education represents a dominant aspect in the rubric of every family's experience, and consists of six strands of sub-themes: (i) information as a source of reassurance and comfort; (ii) the importance of family preparation as a precursor to family coping; (iii) the importance of family preparation in dealing with changes in the injured family member; (iv) the need for preparation in dealing with changes in roles/relationships; (v) the importance of education materials, informational resources, appropriate instruction techniques, gaps in family education programs; and, (vi) the need for advocacy/awareness initiatives for the prevention of traumatic brain injury.

Families repeatedly identified information as a vital source of reassurance and comfort. Underlying most conversations, one got the impression that information served to both alleviate families' anxiety and frustration, and support them throughout their emotional adjustment and adaptation to trauma. As one woman confessed, "I felt that the staff at [*] were much more supportive, understanding, and compassionate than at [*] Hospital. The [*] actually gave me a glimmer of hope. So, he was great." Another participant established the link between information and coping more explicitly when she explained, "Once I met [*], I understood the situation a little better. That helped me cope better." Another mirrored,"The [*], two or three times, did come out into the emergency ward and explain to me things they had found, the fact that they had to operate, and why,
and put my mind at ease that way."

While some participants stressed the importance of practitioners' ongoing and regular explanations of their injured family member's condition throughout the entire rehabilitation process, others emphasized its particular importance to them during the trauma phase. Caregivers felt the reassurance that comes with being informed. One woman articulated, for instance, that "the hints that she [injured family member's [*] gave me made the frustrations less for me, personally." Similarly, another stated, "information reduces the anxiety for me. I can face the truth... what I know, what's really there. But it's the not knowing... ."

Participants consistently articulated an appreciation for [*] practitioners who regularly updated them on the status of their injured family member's progress. One woman shared, "You know, he'd [*], tell us what was goin' on with M. and he was very, very helpful that way." Similarly, "They [*] were very informative, explaining what procedures were being done so that I had a better understanding."

Another reiterated,

And I was impressed in both hospitals, both at [*], and at [*], of the team approach where we did have all those rehabilitation personnel who were working with J. included in the team so that I was up-to-date and they clarified things for me, so that I was more relaxed and able to deal with J.

Another similarly stated:

And he [*] explained situations, and where M. was coming from, and what were his hopes as far as what we could do in the future. And sometimes, M. would sit
I found that very, very, very helpful.

One informant spoke of the much-appreciated family education sessions offered at the various hospital and rehabilitation centres: "These were questions that caused a lot of anxiety for each of the members of the family, and a lot of this information just clarified things for all of us." Still another informant relayed her feelings of comfort whenever a specialist's manner of informing the family was perceived to be appeasing and relaxing by the caregiver. "He [*] did explain the possibilities of what it might be, and the repercussions of those, and he put me very much at ease in the way he explained."

Repeatedly, the provision of information as a coping mechanism was clear and unequivocable.

A second and interrelated sub-theme concerns families' descriptions of the importance of family preparation as a precursor to coping. Families allegedly lacked a vision of what the present and the future entailed for both the injured individual and the family. They wanted an explanation of their injured family member's condition and anticipated projections regarding outcomes. They wished for a glimpse of what the future would hold, a snapshot of how family members would behave, feel, and what they would experience following trauma.

All families underscored the necessity for additional education relating to the nature of brain trauma as a means of accelerating/facilitating their acceptance and adjustment to trauma. They expressed a desire for additional information, particularly with respect to the nature of their injured family member's recovery process (i.e., expectations regarding outcome, period of recovery, foreseeable challenges facing both
the injured individual, and the family as a whole). As one man divulged,

It's important, first of all, to understand what the injury means -- that's the education part of it. It's important to be given a clear explanation of what's occurring. Secondly, to be forewarned as to what will occur in terms of my son's recovery, during his recovery. Ah, but also, and side by side with that, is to be forewarned in how I will behave, how I will feel, what I will go through.

Someone else emphasized,

I want no hypothesis or speculation. I want the facts. And I can deal with the facts that I have to deal with. That's the reality of living. I want more explanation of the injury, and uh, what I can expect. I guess I can do a lot of reading, but, when I'm dealing with rehab support services, I would like to get as much explanation of the injury related to my husband at different phases. Um, and the possible repercussions, um any difficulties that we could possibly run into.

Similarly, as one woman dramatically put it,

It's difficult to predict exactly, but what is the length of time that we are looking at in an injury of this type? I mean, it's not like getting over surgery! What I'm trying to say is, "let us know honestly. Is it going to be short-term recovery? Is it going to be one year? Is it going to be two years? Is this permanent? Um, what kinds of things do we have to face as a family, long-term?"

Another caregiver disclosed that,

Our present needs, I believe, would be to still be able to talk to a professional about how we feel. I'm not sure whether we re-invent the wheel in coping skills --
but, I can't help thinking that, somewhere out there, there's a professional that can help us with coping skills.

Such preparation was considered vital in alleviating families' sense of anxiety and stress. Depending on the stage of recovery and their ability for participation in care, many participants also advocated for the inclusion of injured family members in such educational meetings.

Without exception, the education of families on the nature of brain injury was presumed to facilitate their personal acceptance of the traumatic event. As one insightful participant explained:

I just think education makes such a difference. If you know what's happening with the brain and why someone's acting the way they are because of their brain damage -- I find that I can accept it more when I understand what's happening.

A male participant similarly commented,

The helpful bit is we could never get enough information about S. And these professionals who sat patiently and catalogued his progress and what they were doing with him -- was tremendous.

Or again,

The most helpful [component of service] were the exhaustive explanations of our son, his injury, the mode of rehabilitation that he would undergo, what to expect... . That [information] was the most helpful. We were always looking for this little bit of hope, this encouragement.

In addition to the need for supplemental information about brain injury and its
effects upon the family, families also reported a gap in education and support services at the community re-entry phase. Despite the varied range of service providers utilized by all caregivers, families consistently described a need for improvements in family preparation when their injured family member returned home following rehabilitation. When describing their experience with their family member's community re-entry process, families specifically relayed a need for additional preparation as to what to expect when he/she returned home, as well as a continued need to support the injured family member.

As one participant stated,

> When my spouse first came home, we were just in ecstasy! I mean, the whole family sat out here with him, and he was telling jokes, and the kids were just literally rolling on the floor, laughing. And I mean, it was just a joy that he was alive and he was our Dad, he was home! But within three days, we had plummeted to "now, what do we do? What do we do now that reality hits?"

Another stated:

> Most laymen don't know and I had no idea about brain damage, I can tell you that right now. Like I didn't know! I thought he was gonna get up and he was gonna be fine. I thought he'd wake up in a couple of weeks, and he'd be reasonably all mended, that he'd return to work, and everything would be back to normal. And that's not what happened.

Another informant echoed one practitioner's admonition that "you will feel like you are being dropped off the edge of a cliff when your injured daughter returns home," stating:
There were no services available to me, or provided to me, or suggested to me, when my spouse left the hospital. So subsequent to him leaving the hospital, it was really up to me to do my research to first find, then access services for myself after he left the hospital.

Another articulated, "When my spouse came home on the 30th of May, I was not prepared! Nooo-body could prepare me for what I went through. Absolutely nobody!"

In line with others' remarks, "I valued the education we received. But then as you progressed, there was a need to translate 'well, what happens next, following all the rehabilitation?'". Similarly, one informant noted, "I would have liked to have seen rehabilitation workers brought into the rehabilitation hospital prior to discharge so that it would be a smooth transfer back into the community." While another concurred that "I think there's a gap in training the family on what to expect when the patient comes home," yet another informant stated,

It would have been helpful for us to sit down with someone and get some clues as to whether it was "just carry on as you always have, love him, give the same kind of, you know, love and support, that you've always done" -- but just something, to help make that transition into the home easier.

Another offered,

I don't feel the videotape and that one family information meeting was sufficient for the transition home. Now maybe had the insurance company been more cooperative, there might have been more of a transition because we would have had a program set up here. But there was no program and J. came home and all he
did was sit and do jigsaw puzzles, by the hour, eight hours at a time... And that was difficult do cope with as a family. How do I help him? How do I, um, stimulate him to do other things, without pushing him? And where are the limits? So there needs to be education, more education... But then as you progressed, then there was a need to translate "well, what happens next?"
The commonality of experience that binds all caregivers' experience is that assistance in coaching families through the community integration phase is sadly wanting. As one woman graciously put it,

We would have liked to have people who understand brain injury, come into our home during the transition phase. Maybe even walk us through it a couple of days with the patient. Not necessarily do it for us, but walk us through, coach us.

A few of the more ambitious informants even proposed ways in which this might be accomplished.

There could be something provided at the hospital prior to a patient coming home, where a [*] could meet with us there, and you know, call us into the hospital. It doesn't necessarily have to be that we go out to another appointment -- somewhere. If we're there visiting, and an appointment is set, it could be a staff [*] that spends an hour with our family over our case.

Another informant later grappled with the form that such support at the community re-entry phase would take:

I think it would be helpful if the [*] followed up with a phone call even, every six months, or every four months following re-entry into the home to see how things
are, to see how the transition is going... . Or maybe it might even be a suggestion to have someone come home with the patient for a couple of days, and say, you know, even live in. And help the family cope with the re-entry process, whether that could be done through a home visit via a [*], or through someone who's had some education in head trauma, maybe home care.

Yet another suggested a need to,

Get into the hospitals and make sure that the hospitals pass along the message that there are rehabilitation companies out there that can make the transition back to the community a little easier, and that they should allow these workers to work along-side caregivers in the hospital prior to discharge, so that the family member doesn't have to start all over again once they get back into the community.

While overall there is a definite need for supplemental information about brain injury and its effects upon the family, and a demand for bridging the gap in education and support services at the community re-entry phase, a couple of caregivers qualified their comments with some positive remarks concerning the education received. As one woman explained, "The education was tremendous! It helped us to prepare for a long-term period of grief and a variety of feelings that we would go through". Another attested, "They [rehab practitioners] were able to explain about my son's injuries and how he was... all the different phases, and what to expect as he would come out of each phase".

At another level, most families also emphasized the need for assistance with emoting or expressing their feelings as a means of helping them to adjust to the trauma. Families disclosed a need to learn to adapt to the changes brought on by the onset of
trauma, and a need to deal with a broad range of feelings including fear, guilt, worry, frustration, and entrapment. Many families suggested that practitioners might impart coping strategies to better assist caregivers in adjusting to trauma and changes that lay ahead. This was considered to be more helpful than the prescribed method of learning, dubbed by at least three participants as "trial and error learning."

A third sub-theme that appeared in all descriptions concerned the need for additional family preparation in dealing with both changes in the injured family member and the concomitant changes in familial roles/relationships. All caregivers described a lack of preparation in understanding their new family member, suggesting either implicitly or explicitly a need to learn how to deal with the changes in their injured loved one. The commonality of experience thus lay in caregivers' feeling ill-prepared to deal with this new emergent personality. With remarkable consistency, caregivers repeated a similar refrain, notably, that their former family member was gone, and there was a need to get re-acquainted with, and adjusted to, the new personality. As one young woman stated,

In retrospect, family counselling or education about brain injury would have been helpful. This should have come from rehab companies. It would have helped me better deal with my sister and, I don't know, be more accepting of her new self.

Yet another explained,

They [rehabilitation practitioners] were able to explain our son's injuries to us, and how he was... all the different phases, and what to expect as he would come out of each phase. And not to be upset if he did such and such a thing, and that it was very normal.
Changes that occur in the brain-injured individual evidently invoke a chain reaction, spurring concomitant changes in all other family members. One woman explicitly addressed the changes in the family brought on by the onset of trauma:

Everything is upside down and changed. And our whole world revolves around this one person. We can't have any natural family time together anymore. The calendar governs where we are, what we do, where we go, who has the car.

Another caregiver spoke explicitly to the point of not knowing how to respond to the new family member:

But it wasn't a family ... for months. And then, when my spouse came home, and was so different, they [the adult children] didn't know how to respond to him. So the whole family, the whole word "family" was just turned upside down. It was... we were dealing with so many changes, so many appointments, so little time in the home that you couldn't be a family.

Yet another informant explained,

I didn't know half of what was going to come. You know, it's all trial and error, and it was really surprising at some of my son's reactions that I didn't know what to do with them a lot of the time.

Not surprisingly, families expressed a desire to learn ways of effectively dealing with their injured family member. Caregivers specifically mentioned "a need to learn strategies to assist or encourage our injured family member with our recovery process".

In this, as in so many other statements, caregivers appeared concerned with the mechanics of how to re-establish the relationship. They yearned to understand what was involved in
the re-integration of family ties, and re-negotiation of family roles and relationships. Such assistance was presumed to improve upon what I dubbed "the disintegration of the family," which was revealed in many descriptions, as elaborated in the following:

The family's certainly grown apart. Our daughter, has no time for S. She's uncomfortable with him, and she and S. used to travel all around North America together with their friends. With my son, he neither [sic] has little time for S. They'll go out to the movies, but that's about it. He's only too glad to relieve himself of S. again, get him home, and in the door.

And again,

For our other children, they looked to our son as being the big brother -- he was the eldest. Then there's a sudden change in roles. Now S. is the little kid, who has to be cared by them. That's a major change for them who have grown up for 23-25 years, looking up to him as big brother and counsellor... . Because obviously, my wife and I have moved from having been parents of little children who need guidance and care, to being the parents of adults who have hopefully learned, and can now go and try things out for themselves. And that has been reversed again.

The spouse of a brain-injured individual similarly stated, "I'm going through a grieving process, because there are a lot of losses that I'm experiencing. And how do you become a wife when some things are taken away from you?"

Surfacing in often subtle and indirect ways, or more directly through explicit description, families expressed a need for additional preparation that would allow them to deal with a reversal in family roles. Participants expressed a need to explore the impact of
traumatic brain injury upon the family's change in role. One woman who was concerned with issues of coping and management, stated, "How do I deal with the fact that I'm suddenly the main breadwinner, whereas I was formerly a homemaker?" Repeatedly, the provision of information was perceived to provide caregivers with a means of coping with role change and reversal. Another advocated for the "need to educate older women [who are spouses of male brain-injured individuals] to assume greater independence," and help ease them with their role transition.

But, no, I think a lot of women, maybe not as much today, but in my generation -- their husbands did everything. So I think if, you know, people in my age group need to be educated depending upon what has happened to them... We were brought up with the men and they were the heads of the family. [With onset of injury] So I changed.

One homemaker-turned-superintendent put it this way,

I enjoy going out and meetin' people. And I've always worked in sales and that.
Now, since this accident, I had to give up the business that I had always worked for and wanted. I'm stuck in here in a building, doing difficult labour, which is very, very heavy... very hard. And I'm pulling the weight of all the decisions that's made in the family. And basically, what I've done, I've taken over my husband's position, and he's taken over mine. And I don't think there is any way in this world that anybody coulda prepared me for this!

Again, such descriptions attest to a need for additional education to support the family through the transition, and facilitate acceptance of their new role.
A fourth sibling theme that is intimately interwoven with its parent theme is caregivers' descriptions of the need for education materials and informational resources to support the learning initiatives of family education programs. Additionally, many caregivers provided helpful recommendations in regards to the manner in which they wished to have information imparted, as well as their preferred instruction techniques for optimal learning in family education programs.

Within the gamut of rehabilitative care, caregivers consistently uttered dissatisfaction with both the quality and scope of educational materials and informational resources offered. Most insinuated, in one way or another, that educational material and resources for brain-injured individuals and families were lacking. One male informant, a particularly avid supporter of the need for increased education and support services, stated,

I was dissatisfied because there isn't access, easily, for the family to get help.

When the family is at home, and wondering "are we right? are we wrong? Is this decision right? wrong?..." For S., we didn't feel there was anywhere we could go for a start. We watched S.'s brother and sister come apart at the seams. And we had no idea where to go for help for them...

Another woman mirrored these frustrations concerning the lack of adequate educational resources, divulging:

There's not anything in place, you know. Like "Here's a book. This is the manual that you follow... " I realize there's not really a manual that you can follow, but someone has to say, "OK. These are the things you can do. These are your
options. These are my recommendations, as a professional in the head injury field."

Similarly, another woman echoed the opinion that there are difficulties accessing information, as she asserted, "I think there needs to be, in the hospital, in the intensive care, wherever... just general education of family physicians... um and what services are out there, and what avenues to take to find those services." And again, "There is a need for more information. Just what is available in terms of therapy for the head-injured person, and just which services are available for family members?"

This gap in families' knowledge of the services available for brain-injured individuals, as well as a perceived need to be educated on the various phases of recovery, and what to expect at each stage, was further reflected in the following:

You need more information on what type of therapy is available, and at least what rehabilitation is available... . Rehab practitioners could provide some sort of a listing by district or something. Some sort of a listing of whatever service is required that would be easy for us to contact whatever we need.

Or again, "If I had had more education on the stages of the process, and healing of a brain-injured person, then the stress might not have been so great."

While the overall consensus was that "there is a lack of written information about head injury," one informant suggested that the site of trauma (i.e., hospital emergency ward) would be an ideal place to offer families much-needed information. Brochures that educate families as to the nature of head injury and what to expect following trauma could be made available, as suggested:
In retrospect, there was nothing at the hospital. There was no brochure or anything like that at the hospital, that would explain what a head injury is, or what to expect over time... But, I think in the initial phases in the trauma, it would be helpful if head injury literature were available for families at the hospital.

In as much as there was agreement regarding dissatisfaction with both the quality and scope of educational materials and informational resources offered, many caregivers again shared similar ideas as to the format such information might take. Most proposed "a directory of available services for both brain-injured individuals and their families." And again, "I think it would be helpful to have a list of the brain injury organizations available." Alternatively, "I think that what is needed would be a card, a simple card, in point form: Facilities available to families." Others indicated there was a need for professionals to better guide families in determining the type of services that would be of benefit to both the injured family member and the family. The need for increased professional guidance was illuminated in the following:

So, um, that kind of thing is a gap: A list of services available and someone who is knowledgeable about the patient to come in and say, "Here are some of the things I think would be helpful because of the types of injury that you're loved one has sustained. In the future, you may or may not need some of these following personnel services, or equipment services."

Another woman articulated that educational resources, far from being unavailable, were indeed in place. What was lacking, however, was knowledge of how to access needed resources, confirming once again the need for increased professional guidance:
There are gaps in the material that is available to help educate family members about brain injury. Don't get me wrong: The resources that are helpful for families are out there. There's a lot of resources in the community, but, when this happens so suddenly, and you've never had to use these resources before, you don't know where to begin, even if you do have a medical background. Umm... your medical background really deals with acute care, and once you get outside of the hospital realm, you really don't have that much knowledge of what is there. And so, I would have liked to have a little bit of guidance about that.

Still others described the need for professionals to be better educated as to the nature of brain injury:

I think the drawback [in the delivery of services] has been professionals' lack of understanding of what a head injury is... that there's not a lot of education out there, or there's not a lot of educated people out there in the field of head injury.

Because this issue is intimately interconnected with the theme of practitioners' qualifications, professionalism and competency issues, we will delve into it more elaborately later.

Caregivers' discontent with both the quality and scope of education also revealed itself in practitioners' need to better educate caregivers' injured family members on the nature of their own injuries. Caregivers repeatedly argued that such education should be delivered in simple language, unfettered by technical terminology or jargon. As one participant stated,
And so, I said [to the *], "Well J. has not been able to comprehend what you have been talking about. Do you have a model of the brain?" And he went and got it. And I turned face-to-face towards J., and was able, in front of the doctor, to re-explain what the doctor had just told us. But in a language and a manner that J. would understand.

In regards to professionals' involvement with education and the educational approaches utilized, at least one informant explicitly asserted the need for service providers to more aggressively seek opportunities to provide education and offer appropriate service. "So, be more ... way more aggressive in educating and providing services. Don't expect the family members to seek you out. You seek them out as a rehab professional." This aspect of caregivers' descriptions will be elaborated upon in further detail during our discussion of the second theme: control.

As far as methods of instruction and techniques are concerned, caregivers offered various suggestions. Many advocated the "use of real-life scenarios" and "use of videotape" in understanding brain injury. As one participant articulated, "Well, in terms of understanding technical terms, for the actual mode of delivery, videotape is excellent. Um... because hearing is not always... well, we know it's not the best way for us to learn." Another caregiver specified in detail the reasons she believed in the use of an educational videotape and brain model as good vehicles for family education:

We had several case conferences in both hospitals where the whole team again was part of the conference. But then they had that special evening where our family was called in with about four or five other families, and that was helpful because
not only was the brain injury visually explained to us through videotape, but also the right and wrong way to handle a patient in the home. Um, the injury was displayed through the model of a brain so we understood that the injury could have taken place through the shaking of the head or through impact, and we had a better understanding of a long-term trauma.

Other caregivers also brought up the helpfulness of concrete brain models, and confirmed the benefits of visual, written information, and the use of videotape and charts as helpful in learning.

They used a lot of visuals to explain to us and give us a wealth of information on brain trauma... They used a lot of concrete materials as well as a video and they also had charts up. But a lot of visuals! And those were lacking at the previous hospital, which would have been very helpful to us at the onset, to help us understand what brain trauma is.

The need for visual material for visual learners, and need for concisely-presented information was again reiterated in the following: "When receiving education, counselling and support services, I guess I want something written down, something I can go over and digest. And it's helpful if it's in point form also... I also think a video is helpful."

All families unequivocally attested to the importance of practitioners' creating an inviting educational environment that was both welcoming and comfortable. "The family education evening was very informative and again, they supplied coffee and cookies to make us feel at home". Or again,
You want to feel comfortable with the person you're talking to. You know, basically, just sitting like this, as opposed to an office. A familiar environment, or sitting over a cup of coffee rather than in a cold professional office where they kinda talk to you. I think that's very alarming to a lot of people. But a comfortable home environment where you feel relaxed... This is very warm and automatically relaxing.

Most descriptions addressed the fact that there was a "greater need for clarity, and simplicity of language" devoid of medical jargon to ensure proper understanding. In line with these recommendations, caregivers felt that rehabilitation practitioners should educate both clients and families at their appropriate "level". By level, caregivers meant that there was a need for education to be imparted in a way that was commensurate with where they are at in terms of level of understanding, vocabulary, personality type, etc. As one woman put it, "The [*] didn't explain things in a form that everybody could understand! They should explain in a clear fashion, straight-forward, no medical jargon. That would've helped me a lot!" Another confessed, "I did talk to a few people from [*] [brain injury association]. But it seemed like they were always 'out there' somewhere. You know, like they weren't at my level. And uh... it felt very frustrating!" One informant mirrored, "What I would have liked is maybe somebody that could associate with what I was going through, and was on my level." Another participant concurred,

Mind you, they were telling me things... but nothing was sinking in. I couldn't... they were using words that probably were better for them to understand... If you have no medical knowledge, you haven't a clue of what they're talking about.
Another more satisfied informant stated, "Certainly being educated, you know, education helps... I was almost like a sponge, I soaked it all up. And for the better part of that education, I understood what people said to me. I found that [education] very helpful."

Or, "Well basically, when we went to the trauma unit at [*], and the quality of care there was very good. As I say, my education wasn't the best. I didn't really know what was goin' on, or understand what was going on."

Other descriptions centred upon caregivers' feelings of being overwhelmed by the education process. Not surprisingly, caregivers' emphasized the need for chunking information into chewable units. While one participant suggested that rehabilitation practitioners be available to help families sift through and integrate their learning, others relayed a need for professionals to support them during educational sessions. Educational support might take the form of a representative who would be willing to "translate the medical jargon into plain English." Again,

Now that I think of it... what would've probably been an ideal situation, is to have somebody like a social worker or caseworker with the person, when doctors were talking to them, which is probably very difficult to do because... But I mean, if [*] had been with us at [*], I think it would've been a lot better. She would've intervened and I could have understood what was being said, and then later on, you know, when I came down to earth, if she had been there, she could've kinda said to me, "Well this is what they meant, G."

The need for assistance with digesting the mass of information relating to the care of the injured family member was again reflected in this comment, "I still think they [*]
over-explain and overtalk. Because, hey, a lot of people just don't understand what they're saying." And again,

She [spouse's caseworker] would make sure that somebody was available to come with us [for education]. And this is what I enjoyed because I didn't have to worry if I missed something when they were talking. There were notes always taken and always rehashed after, which was easier for me.

In addition to the necessity of training the family on the nature of head injury, there was also a need for a practical, hands-on approach in educating families as to the nature of brain trauma and how to deal with the injured family member. Families felt it was important to adopt an approach that was relevant to real-life experience, rather than one that was purely theoretical. I often heard families say, implicitly or explicitly, that it was important that practitioners understand caregivers' needs in order to deliver appropriate and relevant education, in the manner that would be suitable to their learning needs or learning style. One informant said, "I think a hands-on approach [to education] is important. In reading the educational material, for instance, I don't want the medical version of it with all the big long terminology. I want the practical side of it." Not surprisingly, caregivers also expressed a need for a holistic approach to family education and client treatment, as mentioned in the following:

Sometimes some service providers look at it from an academic point of view without the real life experience. I think that there is a gap in the services that are provided. Service providers don't look at the whole person... the whole person's life. They don't look at the head-injured person, their spouse, or the family
members... a total life with medical, vocational, and family needs. But they should look at this whole, total picture.

One spousal dyad, in particular, were strong advocates for the need for concrete, specific, and relevant help. Rehabilitation practitioners' help, in their opinion, was consistently characterized by a lack of concreteness and specificity of information. One spouse complained,

There seemed to be a lot of promises. Various people would tell us, "Oh, these facilities are available... ." But, we never were able to get a name, an address, somewhere to go. ... There is confusion as to what's available. I couldn't even tell you right now what's available for a family.

In subtle and less subtle ways, he asserted the need for concrete, focussed, and specific assistance:

But they were never able to say, "Ah yes, here's a phone number, and a name and address. Call this person up and they'll look after you. They'll help you." That never happened... . What I saw happening is nothing. Nothing was concrete. There was always this tantalizing offer, you know, there is help available. Just as the same as they would say, well you can get home help , you know, for S. We would ask the management people to help us out with that, and we would never get an answer.

In a sarcastic tone, this informant later explicitly stated, "Families need focused help - that is, very focused and specific. And again, I related back to the promises that are half-spoken. You know, 'You can get help, and feel free to ask, and don't hesitate"
chuckled).

A spouse reiterated,

My suggestion, if I had my way -- I would have a printed sheet that says, "Here is the kind of help that you need." Because we don't know -- do we need psychiatric, psychological, financial? -- we don't know. It's by trial and error that we have learned! And, therefore, I think at that time, the family needs some strong arm that says, "Here's what you are going to be doing tomorrow. You're attending this building, you're going to be there, this person is waiting to see you, and they're going to talk to you about what you're going through."

In receiving education, family needs to feel they fit with other learners' circumstances to derive benefit. Learners must be comparable in terms of outcome, injury type, date of onset, etc.: hence, once again the need for customization to the appropriate audience:

We did join [*] [brain injury organization] and we went to a couple of meetings. We really didn't find them very helpful. We went a few months after S.'s accident during an all-day meeting... . I think it was just different people getting up and talking about their experiences. And everything had happened years and years ago, and we really didn't find it that helpful.

The timing of the intervention is critical, as expressed by one woman, "But I guess the time when you get it [education] is very important. Um, I needed education, immediately after the accident, and given to me in doses that were in respect to the stage that I was at." Another stated, "Once I met [*], I understood a little better the situation.
That helped me cope... But as I say, I wish it had come earlier on, not later [the education]." Most informants communicated in one way or another that education was especially valuable at the outset of injury, although it was welcomed throughout the course of the recovery period as well. The largest gap, in this respect, concerned education at the community re-entry phase, as reported previously. At all phases, caregivers wanted the education to be commensurate with the family member's stage of recovery and adjustment process. In order to do this, practitioners would have to constantly perform needs analysis and be willing to customize information to each particular family. As stated, "I don't know exactly when the proper time woulda been for education. Yeah, I think it coulda gotten done a little earlier, because everything was done more so when he got home."

Caregivers expressed unanimously that there was a need for rehabilitation practitioners to increase advocacy initiatives on behalf of their brain-injured clients. Advocacy efforts should raise community awareness regarding the nature of brain injury and its effects. There is also allegedly a need for specific knowledge and understanding of traumatic brain injury, and its differentiation from other types of disabilities (i.e., stroke or spinal cord injury). As one woman explained, such efforts should pave the way for greater community acceptance of brain-injured individuals so that, ultimately, enhancement of quality of life becomes a realistic and achievable objective.

I felt that there was nowhere where my daughter would be accepted. I felt that the school system didn't know how to handle a returning brain-injured student. I felt that we were operating in a vacuum... that no one I talked to had ever dealt with a
brain-injured student wanting to go back and play baseball or skate. You know, they'd kind of look at you and say, "Well, she's brain-injured. She can't do these things"... like, they didn't want her as a member of their group. And I had a lot of difficulty getting anybody to let her try. And so I think there's a lot of work that needs to be done in raising the awareness of the possibilities... if you let these people try, and you work with them.

The need for professionals to impart awareness of brain injury to the larger community to facilitate the injured family members' community integration was reiterated again in the following:

I would like to see a lot more awareness in the community about brain injury and that it's not something to be afraid of because this is my impression of how the community sees brain injury now. I can see whenever it is mentioned, the red flags go up and people don't want to have anything to do with brain injury. So I would like to see that turned around. That, to me, is a very great need at this point because of the high incidents of brain injury. We need to feel that these people because they've been rescued, deserve a quality of life, not just an existence.

Another caregiver spoke explicitly to the need for professionals to advocate on behalf of the injured family member and its direct effect on accessing appropriate services:

And I think what happens to head-injured people is that if they don't have an advocate... if they don't have a professional or family member advocating on their behalf and making those kind of steps, then the head-injured person is just going to do whatever they do on their own and they're not going to access needed services.
In line with previous descriptions, one participant pointed to a need to educate the insurance companies on brain trauma since, under the current legislation, such organizations are the stakeholders of funding, and, therefore, access to needed services. This caregiver discerned that advocacy initiatives directed at this target may result in greater cooperation with respect to approving treatment plans, thus reducing caregiver stress:

If it's going to be a long-term thing, someone needs to communicate with the adjuster the situation, and educate the adjusters on brain injury. Because that's where families of brain-injured people run into problems. The insurance people do not understand the implications of brain injury.

**Control**

Threading all participating families in this study, is a second major cluster of themes -- control. The universalism of these descriptions was striking, as with the theme of education, though the theme of control wears many different faces by comparison. Of eight participants, all related in one way or another the challenges in either maintaining, or letting go of control. Descriptions involving control issues centred on a range of intense, negative emotions: helplessness, anger, resentment, frustration, guilt, uncertainty, doubt, rumination, and worry. Other descriptions focused upon a need for normalcy and a return to the way things were. Yet other descriptions emphasized the sense of burden, stress, responsibility, loss of independence, and feelings of being overwhelmed engendered by the onset of brain trauma. Finally, control was expressed in some families' lack of
assertiveness or passivity in regards to help-seeking behaviour, or lack of competence and resourcefulness in learning about programming for either their loved one, or themselves. Included in this thematic cluster are also various statements that underscore a dire need for more proactive service provision.

Helplessness, frustration, desperation, uncertainty, doubt, rumination, and worry characterized all descriptions. The range and evidence of such emotions were wide and varied. Some helplessness centred upon concerns about an ambivalent and uncertain future, as articulated in the following:

What's in the future? What should we be doing as parents to help S., to make him secure? Because I think only by knowing that we are making him secure, will we feel any way happy at all. Whereas we worry night and day, about where he's going, what's going to happen to him?

A spousal dyad were concerned about the future of their injured son, and equally aware that their other children might be preoccupied with the future care of their injured older brother: "There's a concern about what's going to happen with him in the future. And I'm sure that they [non-injured children] are thinking 'will they be stuck with him?"

Not surprisingly, a few caregivers expressed feeling stuck in their predicament and, in such instances, helplessness surfaced through their descriptions. Underlying caregivers' feelings of entrapment was a basic self-perception as powerless victim characterized by a relinquishing of control and a lack of consciousness in the power to exercise freedom of choice. One woman confided, "I'm stuck: I'm in a job I dislike. My life has been a complete change-about. My husband is not the man I married. G. feels stuck."
Another disclosed,

It's wonderful to have children. But sometimes you're just left by yourself. I don't know if there's too many women -- I think the only word you can use is as "ignorant" as I am on this subject, or in the medical field as I was. And I think this is where my big problems were. The traditional housewife who works in... . I'm feeling very pressured, very left out, very manoeuvred. Because I'm being manoeuvred into a position I don't really like.

This same woman expressed feelings of resentment and anger over her perceived lack of choice in being forced to assume her new role as breadwinner.

I couldn't cope. He [injured spouse] was so frustrated because he couldn't do everything and I was having to do it. It caused me all kinds of problems. And I was very angry because I was put in a position of having to do his job. I just hated the job. Oh unbelievable! I didn't want to do it. But I knew I was trapped. I had to do it. I had no choice. So that put me down.

In addition to feelings of entrapment, caregivers recounted their sense of powerlessness in helping their injured family member. One woman spoke of her feelings of guilt and frustration at her helplessness in assisting her injured son to deal with issues of loneliness:

My son was here last night, and he seemed to be very lonely... . I don't know! I don't know what to do, you know, when M. goes through these... these problems. I just feel like my hands are tied. I don't really know what to do for him. It leaves me in an awkward position because I feel I should be doing something for him.
Caregivers also unanimously relayed feelings of frustration in observing their family member's struggle through the extensive re-learning phases of the rehabilitation process, while feeling powerless to help. In such cases, participants voiced an intention to escape their predicament, either literally or figuratively. One caregiver spoke about her difficulties in coming to terms with the fact that her injured son could no longer perform a simple, child-like activity during his physiotherapy session:

When my son underwent rehab, that was a whole new ball game. That was just ... it was devastating! Like it's one thing for a Mom to have a child and go through the different stages. You know, walking, talking, feeding... . I was tied into that with M. certainly, but after his accident, we had to do it all over again! I remember the first day that I saw him walking, it was devastating! You know, with the bars, and he was just holding on. And it was devastating! I would get there early in the morning and this one day, they were playing with this big red ball. And when I looked at M. over it? He kept falling. I wanted to stand up and show him how to do it. I kept thinking "I'll be here for you." But, I saw it, and then I watched M., then I thought, "No, I can't watch this." So I explained that to the [*] and I left for a while. But it was very traumatic.

Similarly, another said, "It [the rehabilitation process] was very frightening for me! I had to learn to do a lot of letting go."

Helplessness, frustration, and uncertainty further surfaced in descriptions relating to feelings of abandonment, or feelings of being stranded by the system. One woman explained, for instance:
And they had a [*] who was trained medically and there was a [*]. We were supposed to ask her any medical questions we had. I think we had about two interviews with her and then she left. She got a job somewhere else and so, during that period that he was at [*], there was no one really available to answer medical questions for us. If we had decisions to make, we had to make them on our own.

Another explained that their [*] contacted the insurance company regarding permission to obtain counselling services but never followed up with the family afterwards, stating, "We just sort of got dropped off." Once again, caregivers' feelings of isolation and the need to reach out for support was epitomized in the following: "I mean, you're in your home, and you feel so alone at times, and you think, am I the only one in the world going through this?"

Control issues surfaced clearly whenever caregivers described intense feelings of anger, resentment, frustration, or guilt since the expression of negative emotions presumably indicates an inability to control and manage one's emotional state. Loss of control was typified by anger directed at various sources. In the following example, the sources of anger were the injured family member, the world, and the participant's children: "I hated my husband. I was mad at him about the accident. I was mad about my whole life being turned upside down. I was just plain mad at the world. And I hated my kids. Absolutely hated my kids!" Or again, "And then the anxiety from the insurance company made everybody angry, until finally, the kids got to the point that they didn't even want to hear the word accident. They didn't want it mentioned. And it was just putting us all under extreme stress."
Similarly, feelings of guilt/frustration surfaced in countless ways, in innumerable instances. The frustration and guilt illustrated in the following statement, related to one caregiver's need for a distress line for family support:

I know I went through these strange periods of times in which I had difficulties coping. I'd be in my office when, at that time I was dealing with a lot of people, in a training environment in working in a very social environment -- and all of a sudden, I would shut down. Shut down because of the reality of what was going on with my son. I was in Atlanta, and in the middle of a very sensitive course I was doing - my mind just shut down and I started to think, "eee Gods, I'm here in Atlanta. I'm laughing and talking with people, as if nothing's wrong -- and my son's lying there in a coma in Toronto." Do you know, at that time, I would have needed to be able to talk to somebody, "help, help, help - please, can I just at least talk to you about this?"

In another example, the caregiver was torn between her desire to take away her injured son's pain, on the one hand, and the realization that she could not do it.

You know, he used to have a lot of friends, and now all of a sudden, like there's nobody. And even sometimes today, he'll call me and ask me to go someplace with him. If I can, I will. If I can't, I feel bad... . I really feel sorry for him, but you know, there's nothing more that I could do, and I have to realize that! You know, that if I could do something, I would do it, but if I can't... . Seriously, it provokes anxiety.
The need for greater control was derived from caregivers' descriptions of the need for normalcy and a return to the way things were. At the same time, the loss of freedom and independence triggered by the onset of trauma was poignant and consistent amongst the self-reports of all caregivers. Consistently, participants reported a need "to move on with life," and to become less programmed by rehabilitation practitioners. In such cases, one got the impression that caregivers felt controlled by a system, entrapped by rehabilitation practitioners' well-intentioned programming initiatives. This aspect of control encompassed a sense that caregivers had lost ownership of their life, of their freedom, of their independence, as they became overly scheduled and structured by numerous responsibilities and commitments. "There was no normal living. There was no opportunities to make any decision for ourselves. All our decisions were being made for us. We were being programmed on what we could do, and what we should do be doing."

Another caregiver asserted, "It's causing more anxiety. The too much programming, the heavy schedules, the distance of having to go to Toronto every day [from Burlington]." Yet another quipped, "We need more time -- free. We need to be less programmed, um, with therapy, so that we can start and resume some type of normalcy in the home. We have to get out and have a little bit of fun, more free time, and leisure." Another offered, "What do we need? We need to get back to whatever 'normal' is. We need to get on with life." Another found a creative way to assert her needs for decreased programming and increased leisure: "That's one thing, I think, that could be done right from the onset so that's it's not three and four therapy appointments a day. But it could be a leisure appointment." Yet another said, "We need more leisure, more time be built into the
therapy so we can live and learn how to be a family again. And not just concentrate on the injury."

Common to all conversations were expressions of **busyness**. One woman captured the essence of her busyness in stating: "I guess we need a lot more time in the day. There's a lot going on." Yet another expressed that, "Another gap [in the services offered], which is personal, is the gap of time for normal living... Having time to go out and have fun, and do extra things that are pleasurable with my husband in a normal, interactive way." Another similarly confirmed, "And then [*] came and the next thing I knew, we've got [*] we're going to, and this and that. I nearly felt like we were smokin' through a room. And then the [*], and it was really hectic there for a while, really hectic!"

Invariably, the need for stability and predictability was subsumed in the need for normalcy, as these descriptions revealed:

"I just wish we were stable and I knew... like he's so sick all the time. Never has a good day. It's not a way of life. I mean, he could get up tomorrow and he could be fine. By afternoon, he's practically dead."

Another confessed,

"There's a need for some stability. I want our lives to be stable. I don't want to feel like we're on a teeter-totter. You know what I mean? Like one day we're up, one day we're down. I just want to go along and kind of have everything, you know... Like it's either we have a good day or a bad day. There's no medium day."
Not surprisingly, most expressed a wish to un-do what was done, a wish to re-write history, and prevent the onset of traumatic brain injury altogether. In such cases, the lack of acceptance of the injury was evident, as the task of meaning making had not fully been embraced. As one woman shared, "I just wish that everything was the way it was. I just wish that everything would go back, [pre-trauma times] and it'd just be easier."

Another expressed the need for normalcy in this way, stating:

I don't want to be a mother or a therapist to my husband. I wanta be a wife. And a lov... and give him the love that he needs and the support that he needs that way, and let him know that he is no different in my eyes, despite that there are, you know, physical and neurological differences.

The need for greater control was additionally derived from caregivers' descriptions of feeling overwhelmed, burdened, and stressed by the onset of brain trauma. Common to all stories were descriptions of increased responsibility and loss of independence. All descriptions were laden with references to the weight caregivers were upholding, their sense of burden, their carrying of a heavy load, their heavy role -- be it concretely, or in more abstract form. One man spoke of being overwhelmed in the context of difficulties with his onerous decision-making responsibilities as a primary caregiver, in relation to the management of his son's health care:

You're trying to cope with this news, the information coming in -- it's information overload -- and another paper is being thrust in your hands to sign up another authorization for another operation on your son. And I don't know what this is really for, and am I doing the right thing?
Others spoke of being overwhelmed by the gamut of rehabilitation practitioners' care, as mentioned in the previous section on caregivers' need for normalcy and a return to the way things were. In these descriptions, there was a common view expressed of life as hectic, of families engrossed and overwhelmed by a host of rehabilitation practitioners who intrude upon their personal space and invade their privacy.

Ironically, in as much as caregivers resented such "intrusions and overtaking of the household," it was common for caregivers to report their need for someone to assume control, and minimize their sense of burden over the care of their injured family member. In this context, caregivers expressed a fundamental need for someone to be strong for them, a need for a reliable source of strength and support. Indeed, most caregivers even seemed to issue a plea for someone to rescue them from their predicament, as exemplified in the following:

Because of what I was having to cope with, and the number of appointments, and my physical health was declining rapidly after my husband came home... . The stress of being the total caregiver, as well as taking over all of the responsibility. I had a weight loss of 60 pounds, and it was coming off rapidly due to stress. And so, [*] [homemaker assistance] was sent in five days a week. And that was the most helpful relief because some days, I couldn't even cope with even getting a meal ready.... . Um, and I set up a schedule for them, and they would just come in and take over. And that left me free to go off to my [*] appointment, which I found vitally important.
On other occasions, participants reported a need for case management services or advocacy initiatives for the family so as to relieve their sense of burden and stress. One woman explained, "She [*] felt that there should be someone who intervenes for the family with the insurance company, and handles insurance matters to take the additional stresses off me." Still another stated,

And I would let the professional - the [*], or whoever, make the decision whether the family needed the help at that time, or whether it should be another level of help. I don't think families should be given that responsibility at that time [onset of trauma].

Primary caregivers' sense of burden and responsibility, as well as perception of isolation in single-handedly managing the care of their family member, plus household responsibilities, was poignant throughout, and is especially well-illustrated in the following: "I had such a heavy load on me, and the children are so busy with their own lives right now with education and working, that there isn't time to help in the home, and so I have been left totally alone to cope with everything." Similarly, another person referred to the trauma in more general terms, stating "it weighs very heavily on you!" Yet another reflected,

And when I look back over the last eighteen months, it wasn't just J. that was hurt. We've all been hurt. We've all been in grief. We've all been in pain. And each one, differently. And to be able to be the mother and take over all of my spouse's responsibilities, financial and otherwise, be the driver, be the homemaker, be the mother. You know... and get to all these appointments. We need to look at life
realistically. That that's overload!

Common to all conversations was a feeling of being pulled towards numerous responsibilities that were traditionally shared amongst various family members. As one woman protested, "And yet, I'm dealing with all of the stress, and the pressures, and the finances, and all of the work that my husband used to do in the home." The need for physical help with household tasks/chores, to replace the injured family member's previous contributions, was further reinforced in the following: "If there was ever anything heavy to be done or work to do, I could rely on S. coming over. He would rush over and help out [pre-trauma]. So that's another thing, is that we need to adjust to a new regime." Another caregiver stated, "I'm finding I'm having to drive J. to his therapies." In speaking about her wish to have her sons understand her predicament, another caregiver, overwhelmed with household responsibilities and feelings of being ill-understood stated: "You know, I need help. You can't always pay for everything. I mean, the children could offer their help without thinking about being paid for it once in a while. It would mean a lot to me." In all of these instances, feelings of being overwhelmed and stressed were clear and unequivocal.

Apart from stress in managing household activities, other reported stressors centred upon the onerous responsibility for caring for caregivers' injured family members, or themselves. The spouse of an injured man suggested that, "It's difficult... you're dealing with ... you're dealing with a third child. Even with small children, you know how long it's been since I've had a third child? Talk about trauma!" Another encapsulated the family stress in this way:
My wife would make her way to the hospital after leaving the office. I would leave my office a little later, and make way to the hospital. We would meet there. We would be there until midnight. We would come home, crawl into bed. We'd get up the next morning. And so, the weeks go on. Weekends were spent trying to organize how we could care for him and take him out. We were up there Saturday mornings at the hospital. And then trying to deal with our own family affairs. Trying to keep things normal within the home. Trying to get some sleep...

Mirroring a similar refrain, another stated: "I totally fell apart in front of her [*] a few times, and she could see the severe stress that we were dealing with here, in the home." In two instances, the family stress was so severe following the onset of trauma, that it manifested itself in disease. As one woman with traumatic stress disorder indicated,

I was beginning to take a nosedive into a depression or showed depressive symptoms. And so I was sent to one of the major hospitals in Toronto, and got the [*] to administer psychotropic medication to help calm me down and relax.

Another alluded to feeling "out of control" in this way: "You know, when you're hit, that's like a rollercoaster. I have very, very traumatic days still, and a lot of nightmares still." Yet another confessed in an extreme case of selflessness,

I suppose I was having a nervous breakdown, in my own way, but I mean, he [injured spouse] was being looked after. And the work here was keeping me so darn busy, I didn't have time to worry about myself.
Another commonality between the majority of caregivers' stories was their expressed disappointment in the quality of care received by their injured family members. Inherent in such descriptions was an assumption, implicit or explicit, that the poor quality of care offered imposed an unwelcome and additional burden upon them as caregivers. In most instances, this ownership of additional responsibility resulted in caregivers' need to assume greater control in caregiving than would have been preferred. In these descriptions, one got the impression that caregivers felt entrapped, resumed to the fate of victim. Few saw that they had other choices. As one woman argued,

I really felt her care was not up to scratch. I visited A. every day for a full year. I didn't miss a day. I was there every day because I didn't feel they [the nurses] were interested in changing her, and feeding her, and supporting her, and talking to her, and playing her tapes that we had there for her. You know, they weren't doing it, and I felt that I had to.

The need for relief of responsibility/burden was typified in descriptions centring upon the desire for practitioners to relieve stress, which was again reflected in this comment:

It would relieve a lot of stress for me, as a caregiver, if a practitioner could assist him [injured individual] in finding something to do that would get him out of the house, and at the same time, he's learning and developing.

Or again,

The thing that was difficult in terms of the quality of service at the beginning was that no one was coordinating this vast number of people that had entered our lives.
as a family. And our home, our front door, was like a revolving door with people coming and going. We began to be governed by the calendar. And I was having to do all of the coordinating.

The need for relief of burden/responsibility was again typified in descriptions centring upon a need for respite care and assistance with the juggling of caregiver tasks: "I was very, very tired driving every day into Toronto. And if there's any kind of volunteer driving services available... because you get so exhausted -- it's almost not safe to even be on the highway." Yet another woman, the sibling of an injured individual, reiterated, "I think my mother definitely needs respite care. She needs to take a break. She needs an advocate for her because she's so tired of being an advocate for A." The need for a support-resource person to lessen the load of responsibility on caregivers' shoulders was again indicated: "The gap was there's no one initially to pick up the ball and run with it, for me, anyway." And similarly, "The atmosphere in the home, and the strain, and the stress that it [trauma] has put on us before we were able to get someone to finally step in and take over that leadership role."

Conflicting data yielded different descriptions which affirmed a sense of relief or indebtedness at having rehabilitation practitioners assume control and minimize family stress. Rehabilitation practitioners were perceived to minimize caregivers' stress and sense of burden whenever practitioners assumed a proactive stance in treating the injured individual. In these instances, participants described feelings of being "alleviated." One woman explained, "They took the pressure off me by researching the various therapies needed for my daughter." Another offered,
Everything worked fine because [*] or [*] would see him and it would be taken care of. Actually, a lot of responsibility was taken off of me because they were coming in, and they were seeing what he needed, and making recommendations.

Another caregiver related,

Basically, everything was very pleasant. You know, a lot of things were taken off our shoulders that we really found relieving. We didn't worry about anything. I mean, when I got the phone call, they said the medical expenses were being taken care of. That was my biggest worry apart from my husband's medical condition.

Interestingly, another identified her lawyer as part of the support network which alleviated her burden and stress: "The lawyer has been a tremendous rehab person because he's taken the stress, a lot of the stress of the insurance company, and having to deal with all the coordinating and everything, right off of me."

Most disturbing to caregivers was their dire need for respite, stemming largely from the loss of freedom and independence that caregiving entails. One particularly open and vocal personality uttered, "What I need is my husband to get out, just for a couple of hours a day. He's constantly there. You need some time alone every day." Another reiterated, "I need to get out. I need to get away for an hour or so, once, maybe twice, a week." Another caregiver mirrored, "That's my biggest problem, you know, is I need a bit of time for myself, and more independence." Yet another expressed frustrations about the loss of independence in this way, stating,

And then my spouse and I, we have difficulties even thinking about holidays. We haven't gone since the accident, together, as a couple, because we feel that one us
always has to be here for our son... I don't want to think that at almost 52, that I have to spend the rest of my living days, feeling guilty about going on holidays. All agreed that their roles since the onset of injury were heavy or onerous.

Another reiterated,

Like, before, my mother could just go out, and there would always be someone home. But now, this past week-end for example, my parents went to their friends' cottage and my mother had to make arrangements for A. Previously, mother would have just gone. So, my mother needs a break.

Understandably, caregivers expressed resentment at the traumatic occurrence because of loss of freedom and independence. The female spouse of an injured individual expressed:

"And I think women look more forward to the time in their life when their children are grown up, and you have that time that's yours. With the accident having happened, it's all gone now." In summary, therefore, what unified/connected all experiences of caregivers, was a remarkable and tragic sense of burden, stress, responsibility, and loss of independence engendered by the onset of brain trauma.

A further commonality between caregivers' stories was the degree of assertiveness or passivity exhibited in regards to help-seeking behaviour. Participants were divided in terms of their competency or resourcefulness in learning about available rehabilitative services for either their brain-injured family member or their family as a unit. Of the eight participants, five consistently described difficulties accessing information and resources, while three displayed competency and resourcefulness in help seeking behaviour. In general, even amongst those who were deemed competent with help seeking, the
consensus was that caregivers' "survival" in rehabilitation circles was largely contingent upon one's degree of self-directedness and self-initiation. Not surprisingly, included in this theme were various statements that underscored a dire need for more proactive service in the traumatic brain injury rehabilitation field.

Caregivers' lack of previous knowledge of traumatic brain injury, ill-informed understanding of rehabilitation and the health care system, and basic lack of competency in sourcing out information and help in regards to available family services, was reflected in these types of comments: "You don't know what services are available to you. And you don't know what to ask for. So you don't know what to expect." Similarly,

I think that basically, the whole system of health that we received was a surprise, a very pleasant surprise. Ah, I had no idea that any of this was available, or what may be available that we didn't take advantage of at the time.

Another caregiver stated, "I didn't know the proper things to ask, at the time, to help me out." Another reiterated, "Well, I guess to help with therapy, you have to know what to ask for. And if you don't know what to ask for, if the help isn't there that should be -- then it's no good for you." Caregivers' lack of competence and resourcefulness in help seeking was again reflected here:

It's just... it's difficult for people to ask if they don't know how to ask for help, or what to ask for. I think, for myself, I guess service was available. I just didn't know what to do about it, or how to go about asking for it, or what to ask for.

Another spoke of her family's lack of knowledge or resourcefulness in procuring counselling services in this way: "And, we had no way of knowing how to go about
getting it [family counselling]. You know, where to go for that type of thing, or whether the family would be able to pay for it." Similarly, "I didn't know how we were going to do it, to get support for the family, that is." Yet another argued,

I guess the services are all quite accessible if you know about them. Like, which comes first? Finding out about them, or accessing them? First of all, you have to know about them, then they're certainly accessible. But, it's the finding out about them I think that presents the problem.

Often, caregivers' difficulties stemmed from a self-reported lack of understanding of their families' own needs. One might speculate as to whether this lack in resourcefulness may have been a by-product of the tremendous stress that characterizes caregiver's lives post-trauma, or an indication of under-developed critical thinking or analytical abilities. As one woman explained, "You don't know what you need, or what to expect." Similarly, another stated: "I didn't know what I needed or who could provide the service," while someone else confirmed, "I just don't think that we knew what we needed. I didn't know what to ask for. I really didn't."

Many of the more passive help seekers recognized in some way that they should have at least requested, if not demanded, service. One caregiver confessed, "Perhaps, as parents, if we had sought help more aggressively [for non-injured son]-- he may not have had to face things alone in his little room in Peterborough [university dormitory]." Others even offered insightful comments as to the reasons for their passivity in seeking help. A male caregiver suggested that passivity may have unknowingly been fostered by the institutional facility itself, where a presumption of competency, efficiency, and expedience
In summary, the key results are as follows:...
may have inspired a false sense of confidence in caregivers, and conspired to invoke passivity:

I think the situation [family's failure to request service] is created by the fact that the injured person is taken into the organization or system -- that we then look to "the system" to provide everything that is associated with that injury. And the system seems so efficient in terms of his survival, keeping him alive, the explanations as we go along (be it brutal or otherwise, as to his injury, his progress and the possibility of recovery). I think there was a tendency to leave it with the system... We made that assumption that the system does this for us. But I should have demanded help for my other son and daughter. I should have asked, insisted on help for myself and my spouse.

Interestingly, another caregiver reiterated a variation on this sentiment as she targeted her feelings of being intimidated by the system, as a central reason for passivity in help-seeking:

When you're stuck in the rehab hospital, you can't get away from the sterility, and it's pretty austere, and it kind of strips you of confidence. It was difficult for you to have authority, or feel that you have the authority to know what's going on.

Yet another implied that things were moving so quickly, that there may not have been adequate time for family to reflect on their needs, much less locate them. This caregiver offered, "I mean how much care do you know that you're getting? Everything was bang, bang, bang."
Other explanations for not demanding service centered upon caregivers' fear of being perceived as self-centred or selfish, if their focus of attention shifted from the care of their family member to the care of themselves as a family. One caregiver summarized,

One, the assumption that it [service for family] is not there. Because the system appears so efficient, that if it's not offered, then it mustn't be there and available to us. And I think, secondly, just the ruling out of oneself and the anxiety to see S. cared for. And, therefore, saying, "No, I suppose we can live without this [family service]." That if we start asking for help for ourselves -- it appears very self-centred and selfish, and we should be caring about our son.

There were also cultural reasons expressed for not seeking help:

And we were perhaps even a little reluctant to do it, or even embarrassed. Our Irish culture looks upon receiving help from an outside agency as a negative downer. To have sought help to cope with things is in our culture an admission of failure.

In a similar vein, another caregiver assumed that her family had to work out its own solution to problems rather than ask for professional help: "I think there would be a tendency for us to say, 'Well, I don't suppose there's any help for this kind of thing. We just have to work our own way out of it.'" Still others were intimidated by practitioners' time constraints and their hurriedness, reflecting the reality of a severely under-funded, and increasingly resource-limited health care system. One of the participants said:

Whereas when you're in the hospital -- here's another thing -- you don't feel that you want to ask questions because these people are hurried, they have schedules.
You see the surreptitious glances at the watches. You know, you see this impatience to get on to the next person because there are three other families behind waiting.

Another expressed a lack of confidence in the quality of information rehabilitation professionals had to offer as another reason she did not actively request assistance. This woman commented, "I wasn't too sure of the quality of information I was going to get. So probably, I wouldn't tap that source, because I didn't think I was going to get what I needed." Interestingly, what these descriptions had in common was a failure to assume responsibility for their incompetency with help seeking. Their high external locus of control placed the burden squarely upon the institutional facility instead of upon themselves as the beneficiaries of service.

By contrast, a select few demonstrated competency, resourcefulness, and creativity in seeking professional help. In these instances, satisfaction with services appeared to be correlated with caregivers' level of self-initiation and aggressiveness. Notwithstanding such competence, however, all caregivers expressed a need for practitioners to impart directions as to available resources for families of the brain-injured. Additionally, caregivers advocated a need for greater proactivity in service provision. One woman asserted,

I feel it's very difficult to, first of all, find the services, and then to access the services. The services that I have received have been excellent, and I think that by virtue of me advocating and seeking them out and finding them... . If someone's family member were injured tomorrow, and they were going through it tomorrow,
and if I were to give them any advice, it would be direction on where to access the services because if they don't go after them themselves, then I think it will be a much more difficult road for them, and nobody will come to them with the services.

Another caregiver mirrored the general perception of difficulties with accessing services, and raised an important question, namely: Whose responsibility is it to furnish the family with needed resources -- the caregiver, or rehabilitation practitioners in an institutional facility? She stated:

How do you find out about them [rehabilitation services]? With a lot of difficulty. I ended up going to a rehabilitation conference at the Convention Centre and interviewing all the rehab companies. And I came home with a pile of information, and sifted through it. I sorted through what I wanted and then approached the rehabilitation company I wanted. But I don't think everybody's going to do that! I think there has to be a lot more done to open up the family members who are caring for the brain injured to the services that are available to them. What I would love to see is one-stop shopping where you could phone a number and say, "You know, I have a brain-injured family member who is X years old. Can you give me the names of some resources that I could call that might be helpful for physiotherapy, for speech therapy, for occupational therapy, for respite care, for community liaison." You know, all this. I would love to be able to pick up the phone and have this right there. It would be great!

Similarly, another aggressive help seeker stated:
Mind you, when I got to [*], I was in for another big disappointment because of once again, everyone kept telling me, "We don't know." I kept saying, "Well, there must be some bank of information somewhere that you can tap and at least give me some ideas." But, they kept saying, "This is a very new field." She should be dead sort of thing, and you know, we rescued her -- what more do you want? And it was just not very satisfactory.

Interestingly, I heard one woman walk me through her step-by-step reasoning as to how she might facilitate her injured spouse's involvement in productive activities. The example nicely illustrated this caregiver's competency, and belief in the importance of a proactive rehabilitative service, characterized by suggestions, guidance, and referral to appropriate sources of help:

Let's say, tomorrow S. doesn't have a job. So, then I would sit here and say, "OK, now we have to get S. out to work, or to volunteer every day. We gotta get him out of the house for two, three hours a day. So, what am I gonna do?" And the responsibility is going to ... the options are to have S. sit at home every day, or for me to go find something for S. to do every day. So, then for me to go find something for S. to do every day... where do I start? So, what I would do is I would call the [*] [brain injury association] office, I would call up [*], I would call up [*], I would call [*], and I'd say, "What do you suggest? Where do I turn? You know, what programs, what phone numbers, what suggestions do you have?"

And then I would follow up from that point on. And in my mind, that is a case manager's responsibility. That is not the spouse of a head injured person's
responsibility.

All aggressive service seekers expressed, in one way or another that, in order to ensure successful family rehabilitative outcomes, they needed self-empowerment and self-initiation skills. When asked about the accessibility of services, one woman epitomized the sense of competency, resourcefulness and self-initiation required in locating appropriate services, as she said: "That was through me making inquiries and getting referrals through [*] and through [*]."

A sibling of a brain-injured individual confessed,

I'm not impressed with [*] or [*] - I'm not sure which - as a family service provider. They've done a good job with A. in terms of physio. The professional companies have done a lot of work with A., but she wouldn't be half as far as where she is right now if it weren't for my mother pushing, pushing, pushing, and advocating.

Not surprisingly, implicit or explicit in a number of descriptions, was the assumption that aggressive seekers who demand service, get service. As one caregiver explained,

If they [brain-injured individuals] don't have a family member advocating on their behalf, and making those kinds of steps -- then the injured individual is just going to do whatever they do on their own and they're not going to access those kinds of services. If you have a person who's advocating and knocking on the doors to get those services or opportunities, those are the people that will get them.

Though there is a self-proclaimed degree of responsibility and burden assumed in caregivers' advocacy initiatives, the net effect is that caregivers' self-initiation positively
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contributes to the enhanced quality of life of their injured family member. In one exception only, a caregiver countered that the struggle or battle entailed in soliciting service was hardly worth the effort: "There's a need for respite care, although just like with the issue of getting a case manager, when you have to fight for something so long and hard sometimes, it's just not worth the effort by the time you get there."

Regardless of caregivers' passive or active involvement in help seeking, the need for a proactive system of rehabilitative care was advocated by all participants in innumerable ways. It was subsumed under the control umbrella by virtue of whether caregivers chose to relinquish the control or responsibility by reliance on a proactive system, holding the reigns of control because of a reactive system, or adopting any variation between these extremes. Repeatedly, I heard caregivers raise the question in one form or another: Whose responsibility is it to ensure that families of the brain-injured have access to available information, resources, and services? Is it incumbent upon the initiatives of family, rehabilitation personnel, other stakeholders, some combination thereof? In countless ways, families felt that rehabilitation facilities should assume greater responsibility since a more proactive approach to rehabilitation care would presumably lessen the already onerous burden placed on families. One woman shared,

I just got a call the other day - I received a call from S.'s employer who was asking me questions about the head injury, who can't get the answers from [*], won't get the answers from [*]'s office but, is looking for the answers from me, and that's not the way it should be. The wife should not be the one being the case manager and managing all aspects of the injury... . I have to be his case manager because [*]'s
office won't do it, [*] won't do it. Although these people are paid to do it, nobody will do it. So by default, in order to move it along, I'll end up doing it.

Similarly, another caregiver expressed her cynicism and bitterness in this way:

We had one rehab company in the beginning and they were useless, and I'm sure, quite a bit of money for their useless service. They were picking my brain. I was going out and finding all the material for them, and I was educating them, whereas it should have been the other way around. And the onus seems to on the clients to make sure that they're getting what they need, not the other way around.

Reiterating sentiments of the system's lack of proactivity in servicing the needs of families of the brain-injured, another uttered: "But again, it was up to me to pursue service. Yet if families do not pursue service, then they need to be pursued."

Primary caregivers often complained of the necessity of approaching their rehabilitation practitioners with their queries, rather than being solicited for offers of counselling, education, or support. One caregiver volunteered, "They [*] did have a [*], but again, you had to approach her; she didn't come to you." Another contributed, "But as I say, there again, it was a lack of knowing, [available services] and on whose part it was, I don't know. I mean, maybe I didn't ask, but then again I don't think anybody ever told me either." Similarly, another stated:

And if I take quality of service to mean service given by rehab, or professional service providers... I'd say that the quality of service wasn't that great -- meaning, that I don't ever recall being approached by anyone, by any professional service provider.
One woman stated,

Had there been a very strong coordinator at the beginning to tell me what was available, to tell me what the Ontario Insurance Commission provides for in head-injured people involved in vehicle accidents -- I didn't have any idea what my rights were.

Hence, the need for rehabilitation facilities to be more proactive and not merely reactive to a request for service is again reiterated in the following:

You need an end. You need someone to say, "You've gotta talk to Dr. So and So. You're set up for an appointment for tomorrow morning 9 am, or would tomorrow afternoon 2 pm be OK?" You may find some families saying, "No, we don't want that." And that's fine. Give them the opportunity to say no, but for goodness sake, don't not give them the opportunity to say yes!

The overall consensus amongst the active service seekers was that the health care system should assist families in gaining competency and resourcefulness in locating appropriate and needed information and services. At the very least, the rehabilitative system should inform stakeholders at the outset of trauma about the range and type of service available to families of the brain-injured.

I don't think the services were very accessible. To be accessible, I think you'd have to know about them first. You know, know their names and how to look them up in the phone book. To be accessible, you have to be known first, and I didn't really know about what was going on. The services I utilized, the ones that I found were most helpful -- I just discovered only four years after the accident.
Caregivers were once again unified in their opinion that the rehabilitative system should proactively state the parameters of service at the outset, including descriptions relating to the service type, availability, and delivery. In numerous ways, caregivers suggested that rehabilitation facilities might establish the parameters concerning what they offer, as well as what clients can, and cannot expect. Moreover, for areas where there are defined service gaps, caregivers expressed a desire to have service providers clearly delineate referral sources for families. A facility's self-assessment and open sharing with clients of their strengths and limitations was presumed to set the stage for clients' realistic expectations of service parameters, thus increasing the likelihood of greater overall satisfaction.

In addition to informing, however, caregivers unanimously articulated a desire for more aggressive and client-centred service-orientation. As one woman succinctly stated, "I think the service industry should be aggressive. The head injury industry should be more aggressive at the start, from the word go, because that's the time of greatest need."

Another caregiver said,

I was never asked if I wanted to go into family counselling, or I was never asked if I wanted some information. So I guess my recommendation is when insurance companies hook you up with a rehab company, you know, the rehab company should pursue it more aggressively.

Yet another vocalized, "So, one recommendation is to be way more aggressive both in education and in providing services. Don't expect the family members to seek you out. You seek them out as a rehab professional." That rehab practitioners should seek clients
out and offer service was again reiterated in this comment:

And the most important thing I think I've been stressing is that the support services weren't free for the taking, if you know what I mean. It wasn't just there for me. I think it's important for service providers to be aggressive in seeking you out and saying, "would this help if you had this?"

A few caregivers in the sample went on to provide a rationale for the need for improvements in service delivery methods. Amongst these descriptions, the common denominator was that certain people may require prompting: the shy, the unassertive, the unresourceful, individuals who may not wish to impose upon others, etc. One woman stated:

I really didn't feel I was serviced. I just really didn't feel like I was on all accounts, at all three stages of the process, I didn't really feel like I received any service. So, there's no quality in nothing. But then again, I didn't ask for it, and if someone asked me, I don't know how responsive I would have been. But no one asked me... And so that's the stage I was at at that point in time. I would have had to have been asked.

Another expressed her lack of assertiveness in this way, stating,

I wasn't given the microphone and told it's your turn to speak, K., which is probably what I would have needed. I wouldn't have stepped forward and said I need counselling. I need, whatever. I would have had to have someone come and ask me a specific question, but no one did. No one communicated with me.

Another argued that families of the brain-injured are under significant stress, and therefore
need proactive service-orientation to help them cope:

But seeking help... it has to be there. In my opinion, it should be offered. Help should be available to the family. You put someone through a trauma, you get poor decisions. A family is not in a condition to make decisions, rational decisions, at this time of the trauma [early onset].

In as much as caregivers agreed that self-initiation and self-directedness were necessary to successfully navigate the system of care, several caregivers expressed feelings of frustration with having to direct or lead practitioners. Their preference, repeatedly, was for service providers to assume the proactive role.

One thing that was helpful, actually, was the ones who would leave notes in S.'s books. They would write progress notes, or write notes to me. Or they'd call me and say, you know, we should do this, or we suggest this or that, and they were good at keeping me informed.

It was common to hear participants speak of their "need for guidance", and complain about practitioners' failure to initiate. As one woman explained,

It's just frustrating sometimes that there's no creativity on the other part that, you know, that I have to make the initiation of um... I have to lodge a massive complaint or suggestion on something. Like, "Geez, why don't you try this, or why don't you try that?, or why don't you listen to S.? This is what he's telling you." And when I did that, it would be respected, and you know, they'd [practitioners] respond accordingly. But it wasn't until I'd do that, that it would be responded to.
The oft-repeated refrain of self-empowerment, which then led the caregiver to obtain service, was once again illustrated here:

And when my daughter was discharged from Hugh Mac, the director said to us, you know, "You're happy to be taking her home, but it's just like dropping you off the edge of a cliff. You're not going to be very happy with everything." I would have loved to have had a referral or a mention perhaps that a rehab company would have been in order at that point. But I didn't have it. And it was through my own research, going to a rehab conference down at the Convention Centre a year after she was discharged from hospital. And I did my interviews with all the rehab companies and I picked one and you know, this is when I feel A. really started her rehabilitation.

In summary, control issues surfaced in a number of ways, ranging from: a broad spectrum of negative emotions (i.e., helplessness, frustration, anger); a need for normalcy and a return to the ways things were; a sense of being overwhelmed, a sense of burden, stress, responsibility, and loss of independence engendered by the onset of brain trauma; a lack of assertiveness or passivity; a lack of competence and resourcefulness in help seeking, and a plea for more proactive service provision. Ironically, on the question of how available were rehabilitation professionals to assist caregivers, I got the impression that service-providers may not particularly care for highly vocal, demanding clients. As one woman explained, "Well, should I say they ran when they saw me coming? I guess they were readily available, but I didn't really feel they had that much to offer." If this were so, then one must question why practitioners did not avert the dilemma in the first
place by simply becoming more proactive.

**Practitioners' Disposition and Character Traits**

A third major thematic cluster, which unified all participating families in this study, and was of particular importance to seven of the eight families, was practitioners' disposition and character traits. Interestingly, the majority of this theme emerged from two primary research questions, namely: "What did rehabilitation practitioners do that you found helpful or unhelpful in coping?" and "What is important to you when you receive education, counselling, or support services?" The theme of practitioner disposition and character traits is comprised of five central elements, namely, (i) the importance of hope, reassurance, and encouragement; (ii) humanitarianism and respect for the dignity of human life; (iii) the value of practitioners' initiative-taking; (iv) appreciation for practitioners' openness and honesty; and finally, (v) satisfaction with practitioner availability and reliability, or what many informants dubbed "just being there."

Of utmost importance to caregivers was professionals' conveyance of hope, reassurance, and encouragement, though the sample was divided vis-a-vis the question of whether or not their rehabilitation practitioners indeed offered hope. Practitioners' attitudes became the vehicle by which hope and optimism, or their opposites, despair and pessimism, were invariably communicated. Caregivers reported being vigilantly attentive to practitioners' verbal and non-verbal cues:

I guess in terms of what I least liked, it's somebody's who's cold, somebody's who's pessimistic, somebody's who's non-communicative. Remember that everything, of
course, is highlighted -- the family is looking for signs in everybody -- either signs of hope, or no hope. Constantly reading into people's expressions.

In countless instances, caregivers underscored the need for imparting hope, and affirmed that practitioners' negative attitude was unhelpful:

The [*] actually gave me a glimmer of hope. So, he was great. However, we were only there for one day, and then we went to [*], and [*] scared me because they were so negative. They didn't think she was going to make it. They just didn't seem to want to share anything with me, to talk with me, because they didn't have any hope, I guess.

Caregivers expressed feelings of upset and anger at practitioners' negativity. Anything that confirms one's value and worth as a human being was deemed valuable. Caregivers unanimously felt that a positive frame of reference would offer hope:

I believe I was at [*] and talking about the lack of support from the staff there, and being told constantly that they didn't know, rather than saying something like, "The brain is a marvellous organ, and capable of a lot of things that we have no knowledge about." This would have been great to hear! You know something positive? Something that you could get a hold of and work with, and give you a glimmering of hope rather than saying, you know, "There's extensive damage, and she's paralyzed, and she's not talking, and she's not responding." It was all so negative, and I would have loved to have heard something just a little bit positive.

And again,
The [*] was very negative. So much damage. It was pervasive. She was going to have many deficits. She was paralyzed. She probably wouldn't ever talk again.

My suggestion was, you know, I think I've seen her move her right side purposefully. "No! That was just a reflex," was his reply. I mean, everything was just so negative, and I came out of there so upset. I mean he gave me nothing. Absolutely nothing! And I would love to walk my daughter back in and say, this is the vegetable you ... .

On the other hand, some of the exceptional and more optimistic descriptions affirmed "some of the [*] were really comforting," or "we were never tired of listening. We were always looking for this little bit of hope, this encouragement." Other caregivers stated, "It's a great benefit to hear them talk with hope," while another recalled,

She [injured individual] was left-handed. That was a real positive for her because the damage was on the left side and so this was something the [*] remarked on. And I thought, "Hey, you know, there's hope!" And he said even though she was so flat when he saw her, because of the history, that she was a good candidate for Hugh Mac, and you know... that just turned my thoughts around that he was a really positive influence.

Another vehicle by which hope and encouragement was offered was through practitioners' enthusiasm and humour. Enthusiasm and humour invariably served to lift caregivers' compromised spirits, and spread infectious energy:

And a couple of the [*] staff were just wonderful. We'd walk in. And one [*] .... [*] was walking down the corridor, singing and she'd say, "Oh, the X family!
Guess what? I got S. to stick his tongue out at me today!"

Another stated,

[*] is superb. They are the best that we have. You know in terms of our assessment of our son's recovery and his care from beginning to end -- [*] would be the highlight. Because we have from the head of the place, the [*], right down to the enthusiastic [*], this team that's looking after him.

Another element of practitioners' disposition and character traits surfaced in subtle ways, and through explicit descriptions of humanitarianism and respect for the dignity of human life. In these descriptions, caregivers were divided as to whether or not they felt they were treated as valued and worthwhile individuals. Although people varied on this dimension, it was noteworthy that all communicated that the issue was an important one for them.

Caregivers appreciated practitioners who treated them with compassion and respect; they articulated a displeasure for those who played the game of one-upmanship: "I felt that I was sort of, almost on an equal, that he [doctor] wasn't setting himself above my husband or myself," and "He talked to me in a way that I felt appreciated." Similarly, it was not surprising to learn caregivers express a preference for friendly, kind, or down-to-earth helping professionals. Other common descriptors mentioned were nice and pleasant. In line with these descriptions, caregivers enjoyed practitioners with a warm, personable, and friendly disposition, who treated the family with sensitivity and compassion:
I am not sure what the text is about. It seems to be a page from a book or a report, but the content is not clear.
The [*] were very friendly. They gave me permission to bring the dog into the hospital to visit J., and the [*] played with the dog on the bed for a while. But very relaxed; they were very relaxed, very human. They'd didn't put themselves above you. They knew you were grieving, and they were sensitive to that.

Similarly, caregivers expressed being comforted by the warmth, encouragement, and empathy of rehabilitation practitioners: "She [*] was just a wonderful, empathetic person, and really put me at ease." Another likewise expressed, "She was very encouraging." Another recalled that, "Rehab practitioners listened to everything I had to say, what I was going through with M. They were understanding and they just knew where I was coming from." Again, "At [*], I felt the staff there were much more supportive, understanding, and compassionate." Hence, a loving and caring approach to client care was highly valued since it reflected a respect for the sanctity and dignity of human life, and a humanitarian approach to client treatment and care.

Overall, the cluster of personal qualities and character traits, which characterized caregivers' dominant experience with rehabilitation practitioners, was considered to be pleasing and meaningful. One informant reiterated the importance of good natured and pleasant personalities, as she conveyed: "[*] is a very easygoing, very nice person." Not surprisingly, a pleasing demeanour was paramount in bolstering caregivers' compromised spirits. Without exception, caregivers preferred accepting practitioners who were warm and caring, as compared to cold, clinical, non-communicative types. One gentleman said,

You see, there were two types of people: there were the cold clinical types, and there were those that had a love of their job, and hence a love of the people that
they were caring for. And we could detect very quickly the difference between the two.

Practitioners' caring and humanitarian approach was additionally reflected in their overall willingness to offer help. Such gracious gestures underscored helping professionals' respect, caring, and sensitivity towards caregivers' feelings and needs. Acts of compassion and kindness made caregivers feel appreciated. "And they [helping professionals] made me feel heard. They were also very helpful and very compassionate."

And again, "I found most practitioners were helpful. They gave each of us that were present an opportunity to ask further questions." Practitioners' willingness to offer help appeased caregivers since they felt that someone was "there" for them: "The [*] were fairly friendly. They tried to help and give us any information we requested."

Professionals' responsiveness and willingness to answer caregivers' questions was again indicated here: "Like I say, the odd time, practitioners got a question they couldn't answer. And they told me they'd be back to me." Another informant shared, "Everyone who helped us -- everyone of them was more than willing to help at any time." The overall impact of practitioners' humanitarian approach on caregivers was that the latter felt accepted and treated with respect, a good springboard for the generation of positive feelings of strength, hope, and courage.

While this was so for many caregivers, a few others felt that practitioners needed to be more empathic, understanding, and helpful: "The [*] could have been a little more helpful, a little more understanding. But I guess you find that in any field." The importance of a humanitarian, personalized, and sensitive approach, indicative of a respect
and dignity of human life, was again reflected in this comment:

Like the [*] who would come in and say, "Ah, excuse me, I'll have to ask you to leave. I have some work to do with the patient." I said, "Excuse me, his name is S." And I wrote a big chart above, Hi, I'm S. and all about him, so that people would understand him when they came in.

Caring, attentive practitioners generally created a climate for a confirming, enabling relationship, rather than a disempowering or disabling one -- with important ramifications on caregivers' self-concept, self-perceptions, and feelings.

Although many caregivers expressed positive feelings about their practitioners' humanistic disposition, a few descriptions focused on a de-humanizing lack of respect for the treatment of caregivers' injured family member, and a lack of sensitivity and compassion towards families' feelings. In one particularly graphic example,

And I related to you the last time we met, about the tremendous experience we had with a young [*] at [*] who was the one person we met who understood what the family was going through. The rest would have us arrive to see S. and have him out on one of these beds with wheels on it in a corridor with a diaper in full public view, slumped down to the side, with his wrists tied so he didn't pull his tubes out. And to them, he was just a piece of meat that they had to look after.

If a friendly, helpful, and pleasant demeanour, and humane treatment of the family were important ideals to strive for in caregivers' eyes, it was equally important to them that practitioners demonstrated increased initiative-taking/leadership skills. Caregivers conveyed a sense that it was important that practitioners assume a more proactive role in
"guiding, directing, and recommending," as discussed in our description of the theme of control. Not surprisingly, professional leadership qualities and the character trait of initiation were highly interrelated with the theme of control (i.e., who should assume the ownership of informing, guiding, and directing families of available services?) For an in-depth discussion of their interconnectedness, readers are asked to refer to the section on caregivers' resourcefulness/competency with help-seeking behaviour, and caregivers' recommendation for a more proactive rehabilitative approach under the thematic cluster of control.

Patience, as a character trait, emerged in other descriptions of rehabilitation specialists' humanitarianism:

One [*] that keeps coming to mind is [*] from [*]. He took his time, you know, it wasn't as if he made you rush. He took the time, and if I didn't understand -- because sometimes, I had a funny look on my face -- he'd explain it again.

Similarly, another stated,

And it wasn't a hurried visit. It was a very relaxed one. One [*] spent 45 minutes with me in his busy schedule. And they took the time with me; I never felt rushed when it came to give me their information and listening to me.

Not surprisingly, caregivers demonstrated an appreciation for highly committed practitioners who were dedicated to their work, and who demonstrated a high degree of personal investment in their careers. They consistently appreciated generous-hearted and giving practitioners who were willing to "go beyond the realm of duty," compared to "those who did merely that which was required":
They [practitioners] would stay late. They would say well... . I would perhaps be coming from somewhere out-of-town. And they would say, well, I can wait here until such and such time. Or, "When do you think you'll get here? I'll wait if you feel you can be here." [Whereas] others would say, "Well, I could fit you in maybe in two weeks' time."

Again,

Regarding availability -- I'd say it was 50/50. There were those who were very obviously under considerable stress in their job. And hence, through no fault of their own, were not available. And there were others who made themselves available, and took a lot of trouble doing it -- and probably paid for it in their personal lives.

For these caregivers, an accommodating, flexible, and adaptive approach to working with clients seemed to be one of the defining characteristics of service-orientation.

Additionally, caregivers expressed an appreciation for openness and honesty. One woman stated earnestly, "He was totally open, totally honest." Another said, "There was no keeping information back." Yet another expressed, "I appreciate the openness and frankness based on reality," thus emphasizing the importance of a true, accurate depiction of reality. I will elaborate upon these findings in further detail under the human relations skills section of the next thematic cluster, entitled Practitioners' qualifications, professionalism, and competency issues.

A final element that characterized the thematic cluster under discussion was practitioners' availability and reliability. This cluster related to trustworthiness since
the defining characteristics of helping professionals are reliability, responsibility, and dependability (Cormier and Hackney, 1993). Universally included in this thematic cluster were various statements that underscored the importance of "being there," by which caregivers meant that practitioners were, for the most part, available and reliable for them, with only a few notable exceptions. It cannot be overstated that "being there" was of paramount importance to caregivers, regardless of the quality of the therapeutic interaction. One woman remembered, "[*] could sit with me and have a coffee, and we'd just talk. It was just basically, that she was there." Another shared, "I think what rehab practitioners have done that is helpful is to be available... to be available for the phone calls." Another reiterated, "So she's [*] very helpful just in being available." Yet another mirrored, "What did rehab practitioners do that I found helpful in coping? -- well, with [*], for example -- her being available for the spousal support group, as well as outside the group." Or, "Whenever I'd call, or I needed to speak to someone, they were always there." Similarly, "So whenever I needed to talk, there were people there". In addition to practitioners' availability, a sense of gratitude and indebtedness was further expressed to the social structures which were in place: "The services that we used as a family -- whether it'd be speech therapy, whatever. It was there."

"Being there" for caregivers was not only reflected in practitioners' physical availability and accessibility, but also through their communicated willingness to help. Caregivers were confident that their questions would be answered, and their concerns addressed: "Right now, I can call her [*] 24 hours a day. She has given me her personal home phone number to call her." Another stated, "Well, we've been kept up-to-date on
our son's progress. And we knew if we had any problems, we could always call them [service-providers]." Another stated somewhat more reservedly, "I would say that rehab practitioners were pretty available to help. If we phoned, they would try and call back. And they tried to help." Yet another emphasized,"He [*] is absolutely outstanding. And for a [*] to give you his private home phone number, his home private practice number, and his hospital number -- you can tell there the quality of care there." Another woman remembered that, "The [*] explained to me what her role was, that she would like to be an ongoing support for me at any times -- that I could call her, or meet with her." Even if the primary service providers were unavailable, caregivers were reassured in the knowledge that there were back-up providers who were willing to assist them.

Practitioners' availability and willingness to attend to caregivers was again reflected in these descriptions: "When we came home, you know, [*] was good. I mean, she answered all my questions, and she asked me what I needed, and that type of thing." Another was appreciative of one practitioner's availability, and ability to listen, understand, and empathize:

There were a couple of times that I needed some questions answered so she [*] was available by telephone. And she would return my calls as soon as possible. And speak quite lengthy conversations in order to support me, and give me information.

Another caregiver repeated a similar refrain,

The quality of service at the trauma phase was excellent. The [*], the [*] staff at the time in the neuro-intensive care unit -- it was one-on-one [*], and they were
excellent. I could call any time of the day. They were supportive. They answered all the questions. They were just wonderful at a very distressful time.

Yet another confirmed the importance of "anytime" availability:

Well the service that I'd gotten, and that the family had gotten, first and foremost, was from [*]. Their services were excellent. I could call them anytime, day, or night. They would get back to me if they weren't in their office.

Practitioners' willingness to attend to primary caregivers' needs again reflected a caring and empathic approach to families of the brain-injured: "Our [*] was just always available for anything that we needed. Any service that we needed, she made sure we got!" Another shared,

I think the quality of care he received in the rehab phase was excellent there.

Generally, the [*] were very empathetic and worked well with S. and myself in providing information and communicating with me. Always open to my phone calls or my questions.

Especially appreciated were moments when practitioners' presence and attention were unsolicited. One woman put it this way,

[*] came up to the room, and introduced herself to me, and made herself available through phone calls. And anytime I was at the hospital, I could call her and she would come up, and we would have discussions.

In another example, the caregiver expressed satisfaction with an [*]'s availability to primary caregivers. She expressed her appreciation in this way,
Our particular [*] therapist has been the most amazing lady. Absolutely marvellous! And she will take the time with me. When I talk to her on the phone, she thought it necessary enough to set up an appointment just for me for next week.

Response to caregivers was prompt, and attention to needs immediate. Telephone calls, for example, were returned promptly:

How available were rehab professionals to assist me? Any time, day, or night. We had [*] home phone number, her office number, her mailbox number, and then if she was not home, she would get right back to us that night. [*] was the same. She had an answering machine. [*] I could phone her. [*]? I could phone her, and leave a message. She'd call me right back. I had no problems that way.

Never!

Another said, "Whenever I phoned her, she always returned my phone call," while another informant echoed sentiments relating to satisfaction with practitioners' reliability by stating, "The [*] phoned back. I wrote letters to him, and he answered them." Yet another caregiver expressed appreciation for the presence of accommodating support staff who did not act as gatekeeper, but were rather willing to facilitate the connection between the caregiver and the rehabilitation practitioner: "When I phoned the [*]'s secretary, she said, 'Call back at such and such a time, and I'll make sure that the time is on his calendar.' And he took the time to talk to me on the phone." Another participant expressed her appreciation over her [*]'s availability on short notice, and ability to listen non-judgementally:
She just sat there and listened to us and, you know, we'd bicker back and forth, she'd just sit there and listen. And we'd bicker back and forth again. But you know, I can still phone her anytime I want, I'm sure, and she will come at the drop of a hat. I think that's important, very important for a lot of women.

Yet another expressed,

I would say, generally, people were very available, almost immediately available.

It's pretty rare that availability has been an issue of concern. Like, once they were accessed, once these practitioners were on board and the relationship had been set up, then they were available.

Caregivers were equally positive in describing practitioners' reliability, with a few exceptions. In one woman's estimation, "The quality of the workers on the whole, was very good. I'd say about 85% were excellent. We had one who just dropped us and never even phoned, and said she wasn't coming back. That was a bit of a letdown." Another commented: "I would say that rehab practitioners were pretty available to help. If we phoned, they would try and call back. And they tried to help."

Despite the predominantly positive comments made of practitioners' availability, there were a few notable exceptions. In these comments, one either heard that being there was not a significant and necessary condition for satisfaction. Alternatively, one heard outright dissatisfaction with instances of unreliability:

Even the morning of M.'s accident - we had all these [*] and whatnot around, that sort of thing. Even though they helped as much as they could, I still felt there was something missing. These well-intentioned professionals -- they were getting M.
to walk and to speak and whatever. They were always there. And that was good.

I liked that, in that respect, because I don't know where we woulda been if we didn't have these... these hospitals and staff there to help.

Another caregiver expressed, "Yes, the professionals were there. But there was that little bit extra that wasn't," while someone else stated: "Because I was away at school, the rehab practitioners weren't that available for me in the beginning." Another caregiver exclaimed, "Only when my daughter was discharged did I have any contact with the [*]. And even then -- my feeling about that, was -- he's just updating his files." This same caregiver also complained about the lack of availability of a [*], as she said:

The [*] didn't talk to me. It was the 18th of January and the accident had happened the 11th of December. It was the 18th of January before I ever got to speak with the [*]. He'd send his residents after each of the evaluations to talk with me. That was OK, but I really would have liked to have had the courtesy of speaking directly to the [*]. I had a lot of problems even getting an appointment with him. He didn't want to see me. And when he did see me, he was very remote, very negative.

Yet another caregiver, who had largely indicated satisfaction with practitioners' availability and expressed feelings of indebtedness to the social structures in place, quipped sarcastically:

I almost got the impression that when things went down, that their shift would be 9-5... . Like if a crisis is gonna happen, it should only happen during the daytime. A little bit of sarcasm there, but that's how they made me feel.
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Professionals' lack of availability outside of regular business hours evidently lent support to caregivers' recommendation for a 24-hour distress hotline for families.

As far as practitioners' reliability was concerned, the only negative comments I heard related to occasional failures in following through on commitments, and some references to vague promises. One man explained,

She [*] was supposed to coordinate S. to go here, there, and everywhere. To different... you know, you'll go here in the morning, go here in the afternoon. And that wasn't happening. It was... we were going on week after week with vague sort of promises.

This participant's spouse similarly echoed, "There seemed to be a lot of promises. Various people would tell us, oh, these facilities were available. But we were never able to get a name, an address, somewhere to go." Practitioners' failure to follow-up on commitments was again reflected here: "And she [*] suggested that we should all have counselling. And she wrote to the insurance company to request funding, but it never materialized. Nothing ever came of it."

**Practitioners' Qualifications, Professionalism, and Competency Issues**

The fourth theme, which wove across the fabric of all participating families in this study, was practitioners' qualifications, professionalism, and competency issues. This thematic cluster appeared in all descriptions, but particularly in six of the eight descriptions -- reflecting a significant aspect of caregivers' experience. The majority of this theme emerged from three primary research questions, namely: "What components of service did
you find most/least helpful?, "What is important to you when you receive education, counselling, or support services as a family member?," and "How satisfied were you by the way in which rehab practitioners communicated with you? Did you feel heard and listened to?" In addition, the three more open-ended questions posed at the beginning of the interview solicited information on this emergent theme. The theme of practitioner qualifications, professionalism and competency was comprised of three key elements, namely: (i) degree of practitioners' professionalism; (ii) degree of technical proficiency, competency, or expertise in facilitating emotional adjustment to trauma (i.e., knowledge and understanding of expertise); and (iii) human relations skills (i.e., communication, rapport building, attending skills).

Overall, the caregivers studied felt that rehabilitation practitioners' lack of professionalism outnumbered instances of professionalism. Whenever professionalism was identified in a caregiver's description, the experience tended to be relayed in the negative, rather than its positive counterpart. One caregiver mentioned his disappointment in hearing one particular professional launch a criticism against another professional colleague:

One other thing, on the unhelpful side, is the criticism of one professional for another. I think we went into this thinking that people were professional because they have a doctoral degree or ophthalmological qualifications, or whatever. And yet, there are professionals and unprofessionals. We discovered that there are incompetent people. But the problem is that, often, we would discover it through another professional's reaction to their name. And that's a little disturbing...
Rather than hearing criticism, I would like to hear people say, "This is a good route to take. This is the person that you want to see if you want to address this or that problem."

The same informant also described the unprofessional conduct of a [*] who lacked an appropriate bedside manner:

The worst experience we had was the third day. We were insisting on someone giving us some progress on S., and a young [*] came out, who subsequently bitterly complained that he had worked long hours, and if he had been in Britain, he would have been paid overtime. But here, they're not paid overtime. This young [*] informed us... he just called us out of the waiting room and my daughter and son were there, and just told us that S. will not recover. He's unconscious. It's unlikely that he'll regain consciousness ever. But if he did, we would be fortunate if he could sit in a chair on his own. He would never know us again. Those were the words of the... that was what we got from the [*]. He subsequently, then shoved a sheet of paper in my hand, and said, "By the way, I want you to sign an agreement that we can do a tracheostomy on him."

Many caregivers complained of the "poor, unprofessional [*] services." In one instance, the poor quality of [*] care stemmed largely from the fact that the facility's [*] placed the injured family member in a rehabilitation bed, rather than a medical bed. In the [*]s' estimation, however, the patient had a medically acute condition, and so the [*] could not justify the injured occupying a rehabilitation bed. Because the medical rehabilitation practitioner failed to impart appropriate directives to the [*] staff, the family became the
Borrowing von Neumann's approach, we can consider the action of a single
computer program as a process that generates an infinite sequence of
strings, each of which is a possible output of the program. The
representation of this sequence can be viewed as an infinite
stream of data, with each element being a string that describes
the state of the program at a particular moment in time. This
representation is formalized through the concept of a state
machine, which is a mathematical model that describes the
behavior of a system based on its input and output streams.

In essence, a computer program can be seen as a
state machine that processes input data to produce
output data, and this transformation is captured by
the formalism of state machines. The state
machine model provides a powerful
framework for understanding the
capabilities and limitations of
computer programs, as it allows
for a precise description of the
behavior of a program in terms of
its inputs, outputs, and internal
state transitions. By examining
the state transitions and the
input-output relationships, we
can gain insights into the
functionality of a program and
develop strategies for its
efficient implementation.

Moreover, the concept of a
state machine can be extended
to encompass more complex
systems, such as those involving
communication and
interaction with external
environmental factors. In these
cases, the state machine model
provides a powerful tool for
describing the interactions
between the system and its
environment, allowing for
precise design and optimization
of systems that must adapt to
changing conditions. Through
the study of state machines, we
are able to develop a deeper
understanding of how
computer programs function and
interact with the world around
us, providing a bridge between
the abstract world of software
and the concrete reality of the
global computing landscape.
scapegoat for the [*s]' frustrations. The net effect was that the family experienced resentment, lack of cooperation, and unsatisfactory service.

And in my mind, that shouldn't be an issue that the spouse of a head-injured person should have to deal with when the [*] has made the move and has accepted S. into the programme... . That it's then his responsibility to deal with his [*] staff. So I'd say the [*] was a real battle... very poor, unprofessional service.

The theme of practitioners' professionalism was further reflected in caregivers' anger for a lack of accountability over rehabilitation outcomes. In one example, one caregiver voiced her dissatisfaction with the fact that a [*] was not able to respond to her questions concerning her spouse's [*] assessment:

There was one other situation where there was a [*] report done of my spouse at the hospital that took all day. And then I was called back in for a meeting.

Someone else was to go through that report with me, and all that [*] could do was read the report. Whenever I asked a question, she said, "I'm sorry, but I cannot answer a question based on another [*]'s report." And so I came away with a copy of the report, but no answers. She said, "I cannot give you any opinions. I cannot explain what he meant... ." See, I was seeing things contradictory in the report to who J. really was. It left me with anger -- this report was being sent to the insurance company. I was angry when I learned that the [*] had never even met J.!

And yet he wrote this 10-page report. He had somebody else do the testing, and he wrote a 10-page report on a patient he'd never even met! And then left someone else to explain it to me, who couldn't even do that! I came away angry,
frustrated, and confused!

Another significant aspect of caregivers' experience was helping professionals' degree of competency concerning their degree of knowledge and understanding of brain injury as a specialization. According to Cormier and Hackney (1993), competence (i.e., expertness) is necessary to transmit and build both confidence and hope in clients. This theme is intimately connected with trustworthiness/credibility since incompetence generally breeds lack of credibility. For the most part, the caregivers studied were dissatisfied with professionals' current state of knowledge, qualifications, and overall competency. Many caregivers, for instance, assumed that a lack of knowledgeable, competent rehabilitation staff was a direct result of the "newness" of the traumatic brain injury field as a young and burgeoning area of specialization. One woman explained,

I think there's not that many quality service providers out there. And I think it's probably because the survivors of head injuries... it's all fairly recent, and the service providers just don't know what to do, or a lot of it is experimental at this point in time. For instance, S. has been back to work for a number of years, but he's the only client that the [*] has who's actually returned to work. So a lot of it is trial and error.

Another shared,

I guess the unhelpful thing is that they're very new at pediatric brain injury rehabilitation so they're learning on the job, and I'm learning on the job. Everybody learns from experience, and we've all grown, I guess, from our experiences, but the next client coming up will surely benefit. That's all to the
good.

Through caregivers' descriptions of family needs, I inferred that another important element of technical proficiency is practitioners' ability to understand and respond to the family's needs. Consistently, caregivers stated that their rehabilitation practitioners lacked the professional training and necessary qualifications to truly understand the family's needs. Overall, the caregivers studied believed that their rehabilitation professionals lacked insight and understanding about the nature of brain injury as a holistic injury, affecting many different systems and functions:

If anything, she's [injured client's [*] jeopardized my spouse's work placement on a number of occasions because of her approach and her lack of insight and education into what a head injury is. She handles S.'s injury like a broken back, or an injured worker with a broken leg or something. She just doesn't have a clue. I'm guessing that he's the only head-injured person that she has ever had on her caseload.

Another articulated in a similar vein:

I don't think she [injured client's [*] could tell you the first thing about what a head injury is, nor could she tell you much more about S., other than his name. I don't classify her as a rehab practitioner, although she should be right up there.

Yet another caregiver expressed rehabilitation practitioners' failure to recognize the uniqueness of brain injury as distinct from other types of disability in this way: "My advice to the professionals is that no two head injuries are the same. That although certain strategies work for one head-injured person, it doesn't mean that that strategy is going to work for someone else." Another similarly echoed,
The other glaring gap that we have found is: when the service is there, and you have accessed it -- it's the abysmal lack of knowledge of how different a head injury is from another injury. We have found one person, a [*], who really understood what it means not only to the victim, but to the family as well. People, when they think of head injury, they think of broken bones and trauma. They don't think of the changes that are occurring within a family, and the coming to terms with something that is never going to be the same again. So when people talk to us - even the rehabilitation folks at the hospitals - they talk to us in terms of well, this is the same as a stroke victim. And we're saying, what?! So again, I believe there should be much more knowledge disseminated to professionals about head injuries. And when I speak about professionals, I'm talking people who deal with head-injured victims ([*]).

On other occasions, caregivers felt that professionals' lack of technical proficiency had little to do with a lack of knowledge or expertise. Instead, instances of incompetency revolved around either commitment of error, carelessness, or inattention to detail. In one such instance, for example, a premature diagnosis was offered without any evidence, causing the primary caregiver considerable anxiety:

One practitioner came out with a definite diagnosis without any tests being done. I had to wait ten months to find out whether it was that. And this [*] was 90% sure, and so that created a great amount of anxiety for me. And even though she was trying to educate me, be informative, and keep me up-to-date -- I found it didn't help. Fortunately, I'm the kind of person that doesn't jump at things like
that. I wait till I have evidence first.

One particular caregiver relayed a distressful situation involving a [*]'s misdiagnosis that occurred due to a break-down in the internal communication of the rehabilitation team:

It was just a total misdiagnosis. We had been told that J. had a micro-aneurism by [*], and that's what she had been told by the radiologist. And the [*], whom we saw, said that my husband didn't have that at all, and he didn't know where the information came from, and he was quite upset. What he was seeing was that there was no way any kind of diagnosis could be given because of the large blood clot in the x-ray.

Not surprisingly, perceived deficits in the competency, training, and education of rehabilitation practitioners contributed to caregivers' recommendation that something ought to be done to fill that particular gap. The staff's lack of knowledge/education and dire need for education in brain injury were further revealed: "The [*] staff did not have the education on head injuries that was needed. Like, the [*] did, but the [*] staff did not." Another woman discerned,

For the ones [rehabilitation specialists] that I've come across that have not been up to my expectations -- I think the drawback has been their lack of understanding what a head injury is. That there's not a lot of education out there, or not a lot of educated people out there in the field of head injury.

Another reiterated that there was a need for increased knowledge and competency amongst brain injury rehabilitation service providers: "I had a lot of difficulty with the [*] staff. And I think part of it is their education on brain injuries -- or lack of education on
brain injuries. And the diabetes in my husband's case just complicated things." Others expressed frustration with professionals' lack of answers, and found a lack of professional accountability unsatisfactory. One woman stated,

At one point, I thought it's better not to get upset about it because, on the one hand, I understood they were all there, and for that, I'm grateful. But when it comes to meeting the family's needs -- you know, they helped as much as they could. And certain questions I asked them, and they just didn't have any answers.

Caregivers also argued that there was a need in the traumatic brain injury rehabilitation field for some type of regulatory, professional body. This body would delineate, disseminate, and regulate the use of standards and guidelines for professional practice as a means of ensuring excellence and quality service provision. One caregiver openly shared,

I have a very big concern about the standards and the quality offered by these rehabilitation companies because it's a very lucrative field, and all kinds of rehabilitation companies have been formed with no real regulating body. And I am really concerned that those who need their services are not getting good value for their rehab dollar. I look at some of the [*] that are out there... .

In a related fashion, others underscored the need for standardization with professional accreditation and training as a means of ensuring the availability of high-calibred, competent, and well-qualified rehabilitation personnel: "I guess this goes back to the standards of qualified staff. You can't just take somebody off the street and make them a rehab worker. They've got to have some background and some training and some
aptitude."

Subsumed under the umbrella of competency, and interrelated to the theme of practitioners' disposition and character traits, were caregivers' perceptions of the need for a creative, holistic, and practical approach to the rehabilitation of brain-injured individuals. There is allegedly a need to see the injured client in a more broad, holistic perspective, rather than as a composite of isolated parts. To accomplish this objective, a few caregivers envisioned that there was an underlying need for practitioners to "go deeper" -- meaning, they would like to see practitioners probe in greater depth, rather than be overly complacent concerning the lack of answers. Expressed feelings of the need for improvement with initiative taking and leadership skill were unanimously made. The need for practical approaches to the treatment and care of brain-injured individuals is nicely illustrated in this example:

And I find it frustrating that the [*] and the [*] can't take it that step further. And the solution there, I think, is a better understanding of the person. Maybe professionals look too much at their text books, saying we have to work on this skill or that skill, from an academic point of view from the [*] testing instead of listening to the head injured person -- saying, "Geez, this person really needs something different, you know, we really have to meet this need. Maybe there's a better way we can come back to this other issue that's burning right now but, we've got to freshen up our rehab approach at this time."

Finally, other elements of technical proficiency identified by caregivers concerned practitioners' degree of expertise in facilitating emotional adjustment to trauma. What is
the relationship of good communication skills to expertise in facilitating emotional adjustment? I believe that facilitating emotional adjustment is an independent skill, while communication may play a role in that skill-set. One caregiver shared, "There has been very little display of anger and she's using humour with her father to help him cope. So, those two [*] have been vitally valuable." Another caregiver was pleased by her [*]'s competence with dealing with emotions and facilitating coping skills: "She [*] was really dealing with my own suppression of emotion, and just getting me through the extreme stress of coping with the calendar." Yet another caregiver reported satisfaction with various consultations with a [*] who assisted each family member in dealing with his/her feelings, and helped him/her develop appropriate coping resources.

"The professionals were stating that it was important not to keep things inside. I know that I have a tendency to suppress my emotions, and I was being very calm for the sake of the children -- but realized later that maybe that was not the best thing to do, that maybe I should have been more spontaneous and let the emotions out... . I'm certainly learning now that the grief process is not helpful if it's kept inside, and that is where the [*] has been a tremendous support to myself. Both of my children are going to individual [*] and my son has been able to deal with the flashbacks of the accident -- because he, too, was in the car at the same time. He's been able to deal with the fear of his own feelings and expressing them. He's become much more open and spontaneous in expressing feeling. My daughter became very angry that this had happened. The very first day she came home from her [*] appointment and was able to say, "My [*] dealt with my anger today."
One's ability to facilitate emotional adjustment and impart coping strategies undoubtedly depends, in part, on the ability to communicate with clients -- which is the subject of the last part of our discussion on human relations skills. It is also remarkably interwoven with the thematic cluster relating to the need for professional and non-professional support as a means of facilitating adjustment to trauma. For ease of presentation, such discussion of competence with dealing with emotions and facilitating coping skills will be interwoven with its related sibling theme, the need for professional and non-professional support as a means of facilitating adjustment to trauma.

Another significant aspect of caregivers' experience was helping professionals' degree of competency concerning their human relations skills. For the most part, caregivers were satisfied with professionals' ability to communicate, build rapport, and attend to caregivers with sensitivity, compassion, and empathy. Apart from the use of occasional long-winded and overly technical/medical terminology, most caregivers were satisfied with the communication process: "He [*] didn't use a lot of medical terms, and if he did, he explained what they meant. So I felt very comfortable with the way he was explaining." Some improvement was recommended in regards to the clarity of the communication style, as discussed under the theme of eduction (i.e., specifically the need to use simple, clear language, void of technical jargon). As one woman admitted,

I couldn't understand what they [*] were talking about. Nothing was sticking. They were telling me things but nothing was sinking in. They were using words that probably were better for them to understand. If you have no medical knowledge, you haven't a clue of what they're talking about!
Other caregivers stressed their satisfaction with the open and reciprocal nature of the communication process with rehab professionals, emphasizing once again the importance of reciprocity and egalitarianism in the relationship with service-providers.

Right now, I think that the rehabilitation company is very good about sharing with me, and in turn, I am quite open. I share everything I have with them -- you know, if I find any research, I'm certainly going to share that with the [*]. And, I would hope that they would do the same. I know that we have gone out together to look at rehab programs... computer programs. We're learning together, so I think they are very open to sharing with me.

Another put it this way, "I was very impressed with the quality of care, the quality of education, for me, personally, from the [*] who were seeing J. from time to time. They were open, frank, honest." Yet another similarly described the communication style as "very open and very honest," while someone else stated optimistically: "I feel we had the best [*] in this city! I was totally impressed with the quality, not only in the care for my spouse, but in the way they communicated with me."

Conflicting data once again presented itself when a few caregivers expressed some dissatisfaction with the communication process. In such instances, the concern revolved around the staff's failure to communicate the name of the attending [*]: "What was not helpful? -- oh, I'd say, every time I turned around, we had a different [*]. So not knowing who was our [*] was not helpful." Another caregiver reiterated the concern about staff rotations, indicating, "We had [*] who kept changing, and never knew who her [*] was."

In other instances, complaints surfaced about the lack of availability of the person of
authority. Consistently, caregivers expressed a preference to meet with chief service providers directly, rather than their delegated resident [*]. In other cases, as indicated in practitioners' disposition and character traits, caregivers expressed a wish for a more humanitarian and sensitive approach in communicating news of their family member's condition. They yearned for service providers with bedside manner, diplomacy, and tact:

The [*] at [*] - he was very abrupt with us. About five days after our son's accident, he told us that S. would be a vegetable. And probably just be in a chair for the rest of his life, and that would be it. Probably wouldn't know us, and he just gave the very worst scenario.

Once again, as described under the thematic cluster on education, caregivers described the importance of regular updates and feedback on their family member's condition: "Feedback is critical. They're [*] very good with feedback." Another noted good communication with her family at the trauma phase, although the focus of care was upon the injured member almost exclusively: Other informants echoed sentiments of a high degree of satisfaction with the communication process at the trauma phase. One woman remembered that, "They went to the first hospital when it first happened, and the service there was absolutely exceptional. They kept coming out every few minutes, and informing us." Still another discerned that, "At the acute phase, the feedback was horrendous. The feedback was brutal." This particular informant felt that,

It got better as we progressed through rehabilitation. I remember one young [*]. She was just unbelievable in terms of how she dealt with it, brought the books in, showed us through her old school books that she had used to study, explaining
what brain injury was, and what we could expect.

At the community re-entry phase, a few caregivers felt that "we got the information, all of the information we needed," while the majority felt like they had been "dropped off the edge of a cliff" into a frightfully unknown abyss.

Another significant aspect of caregivers' experience was helping professionals' degree of competency concerning their ability to express support, empathy, and understanding. This type of human relation skill was identified by all caregivers as being of paramount importance. Expressions of support, empathy, and understanding appeared vital as a means of conveying courage, hope, and faith to caregivers. Throughout caregivers' descriptions of the importance of empathy and understanding, the sub-theme of support was inextricably interconnected to the theme of being there/availability. As one caregiver explained, "At the trauma phase, the [*] and [*] were supportive. They answered all of my questions. They were just wonderful at a very distressing time."

Another expressed, "You know, they [*] could understand, and they were there for me. [*] and the support systems were there for me." Still another reiterated, "I could always call up [*], or [*]. I'd call up [*] and say, this is what's happening. And she'd always be available to talk to me, or S., or deal with his work, or you know, restructure something."

The crux of caregivers' perception of competency with human relations skills centred upon caregivers' satisfaction with being supported, understood, and heard. One woman shared: "I felt so supported [by injured spouse's [*], so understood. She listened." Another rhetorically stated, "What's important when I receive education, counselling, or support services? Very important that you understand. You understand,
and really understand... " Another recalled that, "The [*] asked how I was handling things at home, and how I was doing personally. I really felt a wonderful sense of support because I didn't know that they provided that sort of support system!" Yet another was appreciative that, the [*] has been the most helpful with me, as far as empathy and understanding of where I am emotionally is concerned. As well as educating me, and answering any concerns that I have." The important role that support and caring play was again illustrated when one caregiver shared, "The [*] was absolutely outstanding! Always educating me and, at the same time, being an emotional support to me as I was going through difficult times". Similarly, another caregiver echoed, "(Referring to [*]) And just being able to vent, and getting that support... I know she's always there for me. She even gave me her cottage phone number to call her up north on weekends. So that's a pretty terrific kind of support!"

Yet another stated,

The [*] in both hospitals again gave me the empathy, the validation, and the understanding of what I was going through. The [*] not only did that -- particularly valuable to me was the validation of my emotions because I was having to keep a lot back in front of my spouse, and I found that very, very difficult to suppress the emotions in front of him. And so, she would give me helpful hints, coping strategies, but stress the fact that I have to take care of myself first.

In all of these and similar descriptions, caregivers related an appreciation for practitioners' support, empathy, and understanding. In a few exceptional cases, however,
caregivers felt that there was a need for professionals to "shadow" a brain-injured individual, the purpose of which is to promote greater capacity for empathy and understanding in helping professionals. In one instance, for example, one caregiver upheld the value of empathy and understanding over theoretical or academic knowledge. This particular caregiver divulged,

To improve the quality of the service to families of the brain-injured, I'd say there needs to be education, more hands-on experience of seeing what it's like to live ... to see really what a head-injured person is like. I think there's a danger with the professionals from the various realms to learn it academically, but not to see it and live it. I don't think even by just kind of seeing bits and pieces in a hospital setting that that does it justice. I think the way to see it live would be through a transitional living centre. Professionals could go in and kind of live at the house there for a few weeks just to get a feel for a day-in-the-life. To get the empathy and to get the understanding of what the head-injured person is going through and how they react to certain things.

Where dissatisfaction was expressed, it was not uncommon to hear participants comment about the insurance companies' lack of understanding and empathy: "We had no understanding from the insurance company whatsoever and, you know, if we had that kind of support, then there might not have been a need to hire a lawyer." There were some exceptions but, for the most part, the group members shared similar opinions in this regard. Neither was it astounding to hear some caregivers say, "So I didn't get a lot of support from the [*] that were working with J. The most amount of support that I did get
came from the practitioner herself -- who is head of [ ]." Included as part of the sub-theme of human relations skills were descriptions relating to practitioners' ability to express support, empathy, and understanding.

Practitioners' willingness to listen and fully attend to caregivers was again reflected in numerous descriptions. The effect of such attending behaviour was an indirect validation of caregivers' feelings, and a sense of acceptance of being treated as individuals worthy of respect. Once again, practitioners' attending behaviour served to reassure and impart hope to caregivers.

Their [practitioners] willingness to listen, first of all, to my questions. Sometimes you stop the [ ] and ask a question, and he kind of turns and runs the other way. And he kinda throws an answer over his shoulder. Others sit down, calmly, give you eye contact. They don't interrupt; they listen very carefully to what you're saying. Some, like yourself, are jotting things down so that they can remember. They're think... you can tell that they're thinking about what you're asking. And then, when you stop asking, they will come back with an answer to the best of their abilities.

Another similarly stated, "She [spouse's [ ] is helping me understand, and she's tuning into my emotions and saying, we've got to get the stress released and you need to take more time for yourself, take a night, go our for dinner with a girlfriend." Another offered, "They listened. They didn't interrupt. And when I asked a question, they waited till I was finished and then they gave me a very clear answer. Then I'd say, I don't understand that term. Could you rephrase it? And then they would." On the question of whether
participants felt heard or not, one gentleman shared, "I would say that there was a 50/50 split between whether I felt heard or not. That we felt heard by a percentage, and felt some frustration by another percentage. I guess that, obviously, personalities come into it."

"Feeling heard" is at the very heart of validating human experience and feelings. Repeatedly, one got the impression that caregivers valued practitioners' attentive listening skills because they demonstrate a courteous and respectful attitude towards one's fellow human beings. The importance of being heard and feeling understood was again indicated: "I think that the quality that I found the most useful was their ability to listen. I valued being able to ask questions." The degree of interest that practitioners demonstrated vis-à-vis caregivers' concerns was also crucial: "I felt listened to. Yup, yup very much so. Whether it'd be on the phone or whether it'd be one-on-one, they were very interested in what I had to say." It is, therefore, not surprising that numerous descriptions related to caregivers' need to talk and to be heard: "She was a very down to earth person. She could sit with me, and have a coffee, and we'd just talk. And sometimes, that's all I needed." Another confirmed, "Yeah, I definitely felt that I was heard, and listened to." Someone else concurred, "What you need... what I think you need there, at the hospital, for somebody like me, would be just somebody who could just sit with you and have coffee, and let you babble on and whatnot." Caregivers' need for understanding seemed directly tied to practitioners' capacity to make their clients feel heard: "What's important to me, when I seek out anything, is I need to have that understanding from the other party. That goes a long way with me." Another caregiver raised a connection between effective
listening and support, in saying:

Yes, I was satisfied by the way in which rehab practitioners communicated with me, very much so. At [*], there was a support system that I had there. They heard what I had to say. That was my biggest support system at [*].

Or again, "They listened to everything I had to say, what I was going through with M. They were understanding and just knew where I was coming from." Similarly, another said, "Everybody was great. I mean, I have no complaints about anybody, through the whole thing. Everybody has been very good. I mean, they listened to complaints." One caregiver argued her point, appealing to the need for informal support, since she felt intimidated by professionals with numerous credentials/qualifications:

The one service I would like to see put into effect, particularly for somebody like myself, is maybe even to have somebody to speak with you -- not a [*], not a [*] -- but just somebody to talk to, that you can, you know... . Like, basically, myself - I'm a housewife. You know, I mean, a lot of people don't have the education that other people have, and it's very demeaning to talk to somebody that, you know, have all these MD's and all that behind their name.

By their interest and willingness to listen, helping professionals demonstrated support and caring for their clients. They conveyed a warm and safe therapeutic climate for client self-disclosure and growth, while empathizing with caregivers' experience.

Again, the sample was split in half in terms of caregivers' descriptions of rehabilitation practitioners' listening skills. Of those who were less optimistic in this regard, some said that their particular helping professionals failed to listen to them:
When our son got to [*], the [*] staff were unable to operate the stomach feeding tube system. They didn't know how to operate it. And so, I called my wife from Atlanta that evening. She said, "You're not going to believe this, but S. has been moved from [*], and they know nothing about him, and they're not listening to me."

Another commented,

We seek reassurance in different ways and asking questions is one of the ways we get reassurance. Some of the rehab practitioners are so professional; they know the job so well. They're lousy listeners. They want to tell. You know, "Here's what's going on. Here's what's happening. Let me tell you this, let me... ."

Still others raised a distinction between listening and hearing, stating that they felt professionals managed overt issues well, but did not adequately address covert issues. Caregivers gleaned that to be more effective, practitioners need to probe in greater depth to extract the meaning of the statement for the caregiver:

I think the biggest thing is just the inability to listen and to respond to a specific concern or question. I would like to have heard people saying, "Why are you asking that I? What is your specific concern with that? Why are you saying that?"

Another asserted that good practitioners address family's underlying, not only superficial, concerns:

I think that probably the most helpful thing is to address the family's concerns. I'll give you an example of that. We have continually been concerned with S.'s
eyesight, and up until very lately, no one has done very much about it. Uh, they rather focus on things that can maximize his progress in other ways. And so, we would keep going on about his eyesight, and people would say, "Well, we have to deal with that later. Now let's go on with..." and they'd just go off the eyesight part. We would watch; the eyesight was the biggest in our minds. You know, if this guy can't see properly, how is he going to function in life? Who cares whether his right side has slight deficits?

Implicit in good communication and human relation skills is the ability to confirm that one's understanding is, indeed, accurate. A few caregivers expressed in various ways the importance of restating, rephrasing, and reiterating as tools to facilitate clear communication. One woman identified the importance of this issue for her, personally, by noting,

I know someone understands when they ask intelligent questions that pertain to what I'm talking about. If I understand you, I'm going to come back with something that's going to be sensible in that way that I'm talking, not something just out of the blue. And I think, then, you'll understand, and you'll think she really understands what I mean. Or maybe you'd even question me on it to make sure the point has been well taken.

Similarly, another implied that professionals do not take the time to check out clients' understanding, as she expressed:

I know you can't repeat to a person every time you see them. But sometimes, you know, you just have to say, "Do you know what I'm saying?" or "Do you
understand what I'm saying? Would you know what this is gonna mean to you, or do you understand what's gonna happen?"

Also implicit in good communication and human relation skills is the ability to develop rapport. Social psychological literature on interpersonal attractiveness confirms that clients perceive counsellors as interpersonally attractive when they appear similar to, or compatible with themselves (Cormier and Hackney, 1993). Well liked rehabilitation practitioners had an uncanny ability to develop rapport with their clients. Demonstration of rapport-building capabilities spanned a wide gamut of circumstances: practitioners' willingness to share or self-disclose, an ability to empathize, a feeling of comfort, the creation of an inviting environment, and the willingness to enter into a discussion with personable small talk. One caregiver was impressed by her helping professional's self-disclosure and overall willingness to share: "One of the staff members, at one time did sustain a head injury. It was very helpful because she shared a lot with me." Another caregiver demonstrated the effects of the halo effect: She inferred a practitioner's level of expertise/competency based upon the helping professional's strong rapport-building skills:

There was one person in [*] and she deserved an award for her ability to empathize. She was tremendous! She remembered our names. She had direct eye-to-eye contact. She's not a North American person either. But that's why I more so appreciated her ability to deal with us in the way she did with tremendous skill. She had obviously developed that with a lot of thought. And we felt very comfortable. And we trusted her, tremendously, trusted her ... you know, she just, and she seemed so capable, nothing was too much trouble.
Another described feeling comfortable with practitioners: "[*] was just like a buddy to me. She wasn't married, and she didn't have children. But she's somebody I could talk to." Another confirmed, "The person who's providing the counselling -- I have to have good rapport, I have to feel comfortable with that person." Another explained that when she received education, counselling, and support services, what was significant to her personally, was, "your understanding, and just basically feeling comfortable with the person you're talking to." The importance of an inviting and unintimidating environment was unanimously raised by others:

The environment is important to me. I think if you're into a stark kind of a medical thing... with the [*], with all kinds of degrees, it's kinda of demeaning a lot of times. So if we were sitting in an office environment, I would not be relaxed. But if it's casual like this, this is very warm and automatically relaxing.

Others reported feeling comfortable when small talk was initiated as practitioners opened the client interview:

I think personally, that instead of just going into a problem I've had -- it's helpful for professionals to kind of ask a few personal questions, just to sort of get to know me a bit. Maybe there's something that they enjoy. You know, something to get you acquainted. And that helps you to relax. I mean if you just walk in and kind of bang into your problem, it's kinda...

For another caregiver, rapport-building skill took the form of professionals' congruence with the clients' life stage:
The [*] was very young -- talking about a marriage and you're talking to someone very young and unmarried herself. Do you see what I mean? So I thought it would bother my husband, but it only did for the first couple of sessions.

The underlying benefit of all such communication was validation. Caregivers felt validated whenever their helping professionals gave them unconditional positive regard, and demonstrated a non-judgemental and accepting attitude of their feelings. To the extent that practitioners made caregivers feel like important and worthy contributors to the rehabilitation team, caregivers reported satisfaction, and perceived service providers as competent professionals. Caregivers consistently reported, in direct and indirect ways, a need to be treated with respect and dignity. The importance of validation cannot be over-stated:

The validation, to me is very, very important. That you understand... even though you don't understand the patient's difficulties, you understand the family's pain... because we're all going through the pain at the same time. To be able to validate, I think is so comforting.

Another shared, "I feel that validation is very important -- almost Number One on the list. Secondly, I appreciate openness and frankness." Another caregiver asserted, "And even if it's not an answer that totally satisfies me -- the fact that they validated my emotion and my concern, and helped me to understand the situation a little better, helps tremendously."

Caregivers also expressed a need for egalitarianism or shared power in their relationship with service providers. All communicated in some way a desire for some consultative process whereby both stakeholders engage in joint, shared decision making
concerning rehabilitative treatment and care. Helping professionals communicated egalitarianism by their openness, as well as willingness to establish an inter-dependent and reciprocal relationship with their clients. One woman stated,

They even offered me a job. So, you know, I think they treat me as almost an equal as far as being a team member in the rehabilitation process. They value my input, and I value their input, and it's a two-way street.

Repeatedly, caregivers alluded to the need to have their input validated, to be included in the rehab team, and to be consulted regarding decision making. One woman stated explicitly, "And the fact that I was included as part of their team made me feel important."

Another similarly professed,

Well, I want to be treated as a knowledgeable person. I don't want to be talked down to. I don't want to be ignored. I don't want to be excluded. I want to be a part of the decision making. I want to have my input valued and listened to. Just like I want to have information of value given to me so that I can listen to it and, in turn, evaluate it.

Equally important to caregivers was professionals' validation that caregivers were not alone in their predicament. Presumably, such acceptance was deemed valuable since it facilitated caregivers' emotional adjustment to the trauma, and therefore, coping:

So the [*] were educating us [during family education evenings], they were taking people's experiences to educate others, and to make you feel as though you were not alone. You know, this is something that everybody's feeling, and everybody is going through.
Hence, the ability to validate played a pivotal role in fostering growth and development, and is thus an important human relation skill of rehabilitation practitioners.

Lack of Family-Focused Service

The fifth theme, which wove across the fabric of all participating families in this study, was the lack of family-focused service. This thematic cluster appeared in seven of the eight descriptions, but particularly in six of these seven, reflecting a significant aspect of caregivers' experience. Intimately connected to the themes of education, control/availability, practitioner traits, the need for professional and non-professional service, and systemic issues, the theme of family-focused service dealt with caregivers' overall satisfaction with the quality of care to their injured family members, but the unequivocable dissatisfaction with the lack of services for families, specifically. Repeatedly, caregivers expressed that they received only indirect support via their injured family members' service providers, and the majority often felt that they did not represent a valid treatment group in their own right. It was not surprising to hear most caregivers report that as a treatment group, they felt neglected and unattended to. However, despite the fact that practitioners were not employed to perform rehabilitative service to caregivers specifically, many did so out of a gesture of goodwill and caring.

Descriptions abound concerning caregivers' dissatisfaction with the wanting quality, and in many cases, simply, lack of adequate family-centred service. Caregivers often asserted that the focus of service delivery remained within the exclusive jurisdiction of their brain-injured family members. The focus of care failed to include and embrace the
entire family unit as a valid treatment group:

There wasn't a lot of help out there for families like ourselves, and myself, and that... I would talk to certain professionals; they run the gambit. And there was a lot of support, and a lot of help, which is only right, for the head-injured patient. But when it comes to the family, it's almost like the ground hasn't been broken, as I see it.

Reiterating the lack of adequate family support, and the system's focus on her brain-injured sibling, another caregiver professed,

As a family member, I personally felt that I was pretty much on my own... that my mom and the rest of us kids were on our own. Maybe I got this impression because I was out-of-town, and in school five days a week, whereas my mom was more involved on a day-to-day basis. She was more in contact with the [*] and the [*], and the like. Even still, there wasn't a lot of follow-up for the family. There was definitely follow-up for A. because, you know, money makes the world go round, and the insurance company is a business. So A. got a lot of follow-up.

Another stated,

And I was told, at one time, that G. was their main concern. And he was the one that had to be rehabilitated. And he was the one that... was number one in their eyes, sorta thing. And he had every possible help available.

In line with these descriptions, another caregiver commented upon the lack of family service at the community integration phase in particular, and was grateful for the assistance of her injured family member's therapists:
There were no services available to me, provided to me, or suggested to me, when he left the hospital . . . . The services we talked about? Those are more services provided to S., rather than services that were provided to me. I guess the services that would have been available to me would have been the [*] in the various hospitals, whom I met initially. They all introduced themselves, but I never utilized the [*]. If anything, the ones that I used were more the [*]. I used them more than anyone else.

Similarly, another caregiver affirmed:

I really didn't have a lot of contact with the rehab professionals. We were dealing with [*] in particular, and I met the service-providers in passing -- if I happened to be home and on my way somewhere, while there was somebody at the house working with A. But it was always for A.

Yet another felt stymied by service providers' exclusive focus on the head-injured individual as the central target of attention:

When we moved to [*], the only family service we would get there would be from an [*]. They just didn't provide that sort of service at the [*] hospital. Once a week, on Thursdays, they would have meetings for the families. But the meetings were just about head-injured patients and how to handle them, and you know, all the benefits and so on, and just about the rehabilitation. So I don't really think that there was any further family service during that period. I don't think that we received anything.

And again,
I think that the gaps are that everything is more or less based... directed towards the head-injured patient --- what's available for them. And it's more or less education, rather than what is a head injury, and how do we cope with it. I don't think there is anything really to help us cope with our feelings, and how to just handle our son's injury.

One caregiver expressed resentment at the exclusive focus being directed to her injured son in this way:

Sometimes I resented the whole focus being on M. all the time. You know, I mean, he had all his players in line, and that's great! But then there's the family. Two different people, and you have to be able to support them both. And besides that, you know, what happens to the family after we get here? With all of these people coming in and going out of our lives. You know, it's like a vicious circle.

Common to all descriptions was an identified gap in family-focused service:

"There is no specific word ever said that says, 'Here is the help for you folks [family]. This is your turn.'" Another similarly contended, "Maybe I was clueless, but I didn't get any family service as such. I didn't seek it, and I would say that the quality of service would be pretty poor throughout."

Given caregivers' perceptions of a decidedly pointed focus upon brain-injured individuals as opposed to a more family-centred client approach, it was hardly surprising that many often felt that they did not represent a valid treatment group in their own right. Many caregivers felt as though they were non-issues, abandoned, deserted, not only by the system of rehabilitative health care, but also by the instruments of care, namely, the
rehabilitation practitioners. Although families were not considered by the health care facilities studied to fall under the traditional umbrella or scope of rehabilitative treatment and care, caregivers were, nonetheless, grateful that they received some indirect support via their injured family members' service-providers. A number of caregivers explicitly referred to their sense of exclusion as a target treatment group in their own right: "But in terms of me, I really felt like I wasn't an issue for them [rehabilitation practitioners]."

Another reported, "At the community re-entry phase, that's when I felt I was being... . Before that, I felt like I was just part of the woodworks. When the service finally came, it was fantastic!" Yet another said, "I didn't really feel like I was in the rehab schedule, or in the scheme of things to be given any kind of rehab for myself." Again, despite another caregiver's gratefulness that professionals' were there for both herself and her family, she nonetheless felt dissatisfied since, ultimately, the family's needs were not well met:

"But when it comes to meeting the family needs... . You know, they helped the family as much as they could. But I think they can probably do better." Still, another noted:

When we went to the trauma unit at [*], the quality of services was very good. The people who came in to see me were also very good. But as for myself -- I would say it's only "fair" there. Only because during intensive care, the family care was good. After that, they kind of forgot about you [the family]. I mean, there was nobody! There was nobody there for us after intensive care. I can't remember seeing anybody -- other than [*], that is. I mean, I didn't meet [*] or anybody till he came home!

Another engaged in philosophical speculation, raising an interesting question as to the
purpose of the system's reactivity. Was it possible that a paternalistic attitude of the health care system might have intentionally encouraged denial in order to allow family members to cope with trauma in the early phases of adjustment?

My point with the rehab professionals... in my view, they didn't do anything to help me cope. On hindsight, perhaps that was helpful because I didn't need to worry about myself. I had to worry about my sister. That may have actually been helpful because I didn't need to deal with my own feelings.

All unanimously agreed that, "there should have been more family support." One caregiver captured it succinctly, affirming, "There should be more family support, not just patient support." As another caregiver recommended, there is a need for a unified, "one-stop-shop" type of concept for the treatment and care of families of the brain-injured:

We have a superb burn unit in Toronto to look after patients' specific needs. We have a superb trauma hospital, [*], that saved S.'s life, to look after specific needs. We have a superb Sick Kids Hospital to look after kids' specific needs. What hospital is there to look after family needs, specifically?

Another envisioned a need for additional family support and increased provision of information concerning the injured family member:

One suggestion is there might be something provided for families at the hospital prior to the patient coming home, where a [*] could meet with us there and, you know, call us into the hospital. It doesn't necessarily have to be that we go out to another appointment. If we're there visiting, and an appointment is set up, it could be a staff [*] that spends an hour with our family over our case.
Still another contributed: "The level of service that the family received? Very poor. I feel that it's disjointed, not focussed." Yet another imagined that professionals might regularly arrange for follow-up with family members to ensure they were progressing and moving along in their adjustment to trauma:

One idea [to improve family support] is maybe the [*] could see my husband three sessions, then see me on the fourth. If she did that on a regular basis, she'd keep me working through the process so that I'd have a good understanding and adequate support.

Another common, yet puzzling, element between stories was that frequently, caregivers defined direct family support by the indirect support received by their injured family member. Of those who described the quality of service as good or excellent, closer scrutiny revealed that they were in fact describing their satisfaction with services to the brain-injured, and not the family, per se. Surprisingly, many were unable to discriminate between service delivered to their injured family member, as compared to service delivered to themselves, as either primary caregivers or family. In the methodology section, readers may recall that considerable time was devoted to pre-framing the research questions during the commencement of all semi-structured interviews. I offered a detailed explanation of what constitutes a direct, as opposed to, indirect service. Additionally, I also clearly explained that the focus of this research study was on the direct services (i.e., those that help the family directly in coping or adjusting to the brain injury of a loved one) and provided examples, including education, counselling, support, etc. Interestingly, most responded as if asked about the indirect services, those that assist the brain-injured family
...
member in his/her recovery or adaptation to disability (i.e., nursing/medical care, physiotherapy, occupational therapy, speech therapy, neurosurgery, neuropsychology, chiropractics, massage therapy, etc.)

Beyond the realization that it was difficult to separate direct from indirect service, some caregivers astutely noted the arbitrary nature of the distinction, indicating that some direct services to brain-injured family members could directly affect caregivers, and conversely, some direct services to caregivers could indirectly affect the injured. Though caregivers reported overall satisfaction with the quality of service to their injured family members, the help was focused on the injured and not on the family, per se. In one description, a caregiver defined direct family support by the indirect support received by her injured family member: "The most important thing was that G. was being looked after, and that was all I really needed." Someone else expressed: "If you're the head-injured person, I think you can get quality services. And that's a tremendous help to the caregiver. That's an indirect benefit to a caregiver, but it can go a long way." Another avowed, somewhat less explicitly,

I registered him into the emergency ward. I sat there for something like 9 or 12 hours. There was no [*] present. I felt isolated from knowing what was going on for many, many long hours. I was not allowed to go in to see my husband, even to let him know I was there. Then, one [*] came out and explained to me about the dislocated shoulder, and then several hours later, a second [*] informed me about the brain injury. So the quality, I felt was excellent... the care for J. was excellent. Another similarly confirmed,
Overall, I have been extremely pleased about the quality of care [for injured spouse]. I showed you a chart with the number of people that have been involved in his direct care here in the home. I have been pleased with the variety of services available. I didn't even realize that some of these people even existed!

Yet another explicitly explained the benefits of indirect support:

If we could find workers in each of these rehabilitation roles, I would say we have found almost the best in most cases. And that has made it very helpful for me. Because they've been able to help coach me in ways that I could be of service to J. at home. So they were directly teaching me. But I finally backed off and said I didn't want to be the rehabilitation personnel at home. I just wanted to be a wife.

Another stated,

How do you integrate the patient back into the home and then back into the community? Well, and that's where the [*] and the [*] are helping indirectly. But they were also wonderful as a direct service to me -- because I was able to express the tremendous frustration that I was having, and um, the [*] particularly was able to be a real comfort and take down the needs/express the needs to the insurance company. They talked specifically to my [*] and what she saw happening in the home. And um, it was a link for me personally -- so now I was getting J.'s indirect service as a direct service to me as well.

The selflessness exhibited by several caregivers, even when asked to describe the quality of family service received, became more remarkable in the following descriptions. In one description, the primary caregiver conveyed the importance of her injured spouse
receiving appropriate care and support, and described its cathartic effects upon herself as a caregiver, "Whenever I take him [injured spouse] back for his appointments, he's constantly linking with those support people. And to me, that was a direct service because it brought happiness to J., which brought happiness to the home." In another striking case, the caregiver expressed a belief that she did not have any need for personal assistance or family service. Instead, she reported feeling vicariously satisfied that her injured spouse was being cared for, and his needs were being met. In this instance, the caregiver's needs were thus subjugated to those of her spouse:

Actually, I didn't need anything. G. was being looked after so I was very satisfied. There wasn't anything I needed at that time. I just felt he needs this, he was getting all the attention he needed. And that was fine. And I suppose I was having a breakdown, in my own way, but I mean, he was being looked after. And the work here was keeping me so darn busy, I didn't have time to worry about myself.

Caregivers' indebtedness to their indirect service providers was another element that bonded these families together. It was not surprising to learn that the indirect support extended to caregivers (via their injured family members' circle of rehabilitative therapists), was generally well-appreciated. One caregiver said, "I really had no support, other than through [*] personnel, the [*], and the [*] coming into the home [indirect service-providers]." Another recalled, "And she [injured's [*] initiated ways to help me, and she was the one, I think, who called in the [*] (homemaker assistance)." Another expressed her general satisfaction with the quality of services to her injured family member in this manner:
Of those services that I've come across that have been good and have had good quality, I have no complaints. Of those that have not been to my satisfaction, I think it's because of practitioners' lack of understanding of what a head injury is. Still another caregiver expressed, "And if I'm having further stress with the insurance company, I can speak to J.'s [*]. She talks directly to the lawyer and conveys for me. So she's an advocate for me as well." Yet another caregiver was grateful to her [*], who took the initiative to book time with her:

Our particular [*] has been the most amazing lady. Absolutely marvellous! And she will take time with me... . And, when I talk to her on the phone, she thought necessary enough, at one point, to set up an appointment just for me for next week.

Others, who were less appreciative of the assistance of indirect service-providers, found them unhelpful because they were not fully attentive to caregivers' needs. One woman specifically asserted: "The least helpful for me -- and this isn't in any negative sense -- was the rehabilitation people working with J. See, 'cause I didn't have any direct reason to have any contact with them." Another similarly argued, "I'm not impressed with [*] as a family service provider. Like they've done good work with A. in terms of physio."

Although the majority of caregivers responded to the question of quality of service by focusing upon the care of their injured family member, rather than family service, a small minority were reportedly impressed with certain aspects of the quality of family service received. One woman expressed her high degree of satisfaction with two practitioners of family service in this way: "The quality of family service was great!
excellent!" On another occasion, one caregiver alluded to the promptness of family service during the trauma phase: "My husband had the accident on Sunday, and the [*] came in on the Monday." Still another indicated, "My rehab is basically the home care [*], and the [*]. They'd be my two biggest and I could not cope without them. They are absolutely vital!"

**Need for Professional and Non-professional Support**

**as a Means of Facilitating Adjustment to Trauma**

The sixth theme, that wove across the fabric of all participating families in this study, was the need for professional and non-professional support as a means of facilitating adjustment to trauma. The professional support aspect of this thematic cluster appeared in all descriptions, and were of paramount importance to all caregivers, reflecting a significant aspect of caregivers' experience. The non-professional support component of this thematic cluster also appeared in all descriptions, but was particularly noteworthy for only four of these. Intimately connected with all of the other emergent themes, the theme of professional support as a means of facilitating adjustment to trauma dealt with six central strands: (i) the importance of case management services; (ii) the need for greater facilitation of coping skills; (iii) the demand for guiding clients towards dealing with their emotions; (iv) the dire need for additional assistance with the community re-entry phase; (v) the request for assistance relating to the re-integration of the injured family member into the home; and, (vi) the necessity for family re-integration services, consisting of the need for additional assistance with the re-building and
strengthening of family relationships and role re-integration. By comparison, the non-professional supports concerned the informal social support networks by which families obtained encouragement and support. Such channels of support included descriptions of the importance of friends, family, TBI family peer support, neighbours, faith, religious affiliations, and the helpfulness of extending support to others in a similar predicament as a means of self-healing and catharsis.

The need for case management services (i.e., a professional advocate who acts on behalf of the injured individual and the family) was revealed, both explicitly and implicitly, in the majority of descriptions. Prior to delving into these specific findings, however, it is helpful to understand the role of case management in the field of rehabilitation psychology. Those in case management services (or rehabilitation consulting services, as it is alternatively called), assume responsibility for the management and coordination of the overall direction and details of the recovery process. Through a comprehensive assessment of the medical, vocational, and psychological needs of referred clients, case managers recommend necessary actions for successful rehabilitative outcomes, and coordinate the action steps of approved rehabilitation plans. Because effective case managers assume full control and ownership of the direction and outcomes of the case, it is hardly surprising that they may often play a pivotal, integrative role in the coordination of all therapeutic modalities.

In this research study, caregivers' arguments for the need for case management services generally centred around anticipated expectations that such assistance would lift caregivers' onerous sense of responsibility. One caregiver, for instance, confessed,
I spoke to my daughter this morning, and conveyed everything to her. She had a good idea: she felt that there should be someone who intervenes for the family with the insurance company, and handles insurance matters, to take the additional stresses off.

Another caregiver similarly articulated, "The gap was that there's no one there initially to pick up the ball, and run with it... for us, anyway." The need for a support-resource person to lessen the family's load of responsibility was again indicated when another caregiver stated: "I think my mother definitely needs respite care. She needs to take a break. She needs an advocate for her because she's so tired of being an advocate for A."

Yet another quipped:

Services can be very fragmented, and I found that there's no... there's no overall management. And actually, I guess that's my biggest bone of contention is that... I think that's probably the biggest downfall of the services provided. Yes, now we're on the point: the biggest downfall is the lack of a case manager, in that I have never had a case manager for S. I have been his case manager throughout the years.

In a similar refrain, another shared:

For instance, when he [injured individual] was in the hospital, he had an [*], a [*], a [*], [*], and [*] but, nobody... nobody looking (.../???) Or, where was the next step, and what do we do from here? Is this working for S.? And that continues on even today. Right until today, where four years later, I received a call just the other day -- I received a call from S.'s employer who was asking me questions
about the head injury, who can't get the answers from [*], won't get the answers from [*]'s office but, is looking for the answers from me. And that's not the way it should be! The wife should not be the one being the case manager, and managing all aspects of the injury. But to be successful for S., to access services, for S. to maintain his employment -- that's what I have to do. I have to be his case manager because [*]'s office won't do it; [*] won't do it. Although these people are paid to do it, nobody will do it. So, by default, in order to move us along, I'll end up doing it. And come to think of it, I'm not sure I know how the service providers could do it. Maybe they could do it. But, I don't know if they'd be successful at it.

Caregivers also consistently reported a need for increased facilitation of coping skills as a means of fostering better adjustment to trauma, within the gamut of professional support services requested, and in addition to the need for case management skills. The need for rehabilitation professionals to help families cope with their injured family member was revealed on countless occasions: "Like, my point with the rehab professionals is that, in my view, they didn't do anything to help me cope." With overwhelming consistency, caregivers expressed a need for rehabilitation practitioners to impart coping skills, and teach them how to adjust to, and deal with, their injured relatives: "We still need the help of the rehabilitation company. That's ongoing. Their guidance, their direction, their therapies." Another similarly ascertained, more explicitly,

What would have been helpful is family counselling or education about brain injury, which should have come from rehab companies. I feel it would have helped me better deal with A. and, I don't know, be more accepting of her.
Yet another requested professional assistance in this way,

There should be family support, not just patient support in the initial stages.

Particularly, where there are children, and young people because they do not have any perception of what has happened. I did. I saw more and more, and heard more and more, and talked more and more, as I was visiting at the hospital. Uh... but the children only went down twice. They couldn't handle it. And then I would try and re-explain at home, and at times, that got them upset, even though I was trying to do it in a way... But I felt I had to be honest that this is the stage that Dad was at, and here was the hopeful comments that the [*] had made, and here were some things we might have difficulty with. And tried to be positive and honest, without being alarming, um... But somebody who's an expert, they could probably take it easier from... than me having to be the one to tell them.

Yet another mirrored,

My son G. had real problems for one year at university afterwards. He was a Dean's honour student and zoomed downwards [following onset of his brother's injury]. Fortunately, he had professors who were sympathetic or empathetic, rather. But, he did, he missed the Dean's list that first year. Perhaps, as parents, if we had sought help more aggressively -- he may not have had to face things alone in his little dorm room in Peterborough. Our daughter as well, we knew that she suffered a lot, because she withdrew herself totally from the family, and she even stopped visiting S.
Other caregivers were more optimistic about the professional support available, advocating that the need for professional guidance in helping the family to cope with the trauma, was indeed, well-met:

Education helped to prepare us, and allowed us to express feelings for how we felt. You know, we all responded in different ways. I handled the initial stage very calmly. My daughter did as well. My son totally retreated -- almost to the denial standpoint. And so we began to recognize that we were each handling it differently. I talked about this with the [*] as well, and learned that it was important to model the release of the emotion in the home.

Of those who consulted [*], [*], or [*] to help them better cope with their adjustment process, several underscored the rather dramatic contributions of these varied helping modalities in fostering coping strategies. One caregiver, in particular, gleaned: "There has been very little display of anger [in primary caregiver's daughter]. She is now using humour with her father [injured individual] to help him cope. So, that [*] has been vitally valuable!" Descriptions heralding the benefits of counselling in invoking better coping skills supported the promise of counselling strategies, in those who were likely to benefit from such interventions (i.e., those with analytical and critical thinking capabilities; those who have an interest and capacity in self-reflection and self-assessment; those with strong verbal communication skills; those with a high degree of commitment to change, and the necessary motivation to assume responsibility vis-a-vis presenting problem, etc.) Helping professionals' guidance in coaching caregivers throughout the adjustment process was once again reflected in the following:
The most helpful was the [•], [•], and [•] at the hospital. Because again, they were centering around my needs, and giving me hints on dealing with the state the children were in at home. My son totally retreating, my daughter, listening and trying to support me, but not really understanding. And the fear that they were going to lose their Dad.

In a similar vein, [•] allowed the spouse of an injured male to better cope with his dramatic personality change:

The [•] was a service to me 'cause G. had gotten so impossible to live with. I couldn't cope. He was so frustrated because he couldn't do everything, and I was having to do it. It caused me all kinds a problems. And I was very angry because I was put in a position... of I just ... I hated the job. Oh unbelievable! I didn't want to do it. But I knew I was trapped. I had to do it. I had no choice. And so that put me down... . But [•] ... , sometimes we'd talk together. Sometimes, she'd talk with him. Sometimes, she'd talk to me. And we just kinda' ... we talked it out, and worked it out. So it was [•] that very definitely helped us through!

Satisfaction with [•], as a means of assisting caregivers with the adjustment process, was again mirrored when another caregiver avowed: "[•] was a very, very important service to me. It was a very good service, and I was pleased with it. I don't know what I would have done without it. I really don't!"

Common to all descriptions, was an explicit statement of the need for practitioners to help the family emote, and deal with their feelings surrounding both the traumatic event and the ensuing life circumstances. For many caregivers, one got the impression that the
opportunity to emote proved to be a calming, cathartic process by which inner peace and tranquility could be achieved. Emoting seemed to be a meaningful, enabling vehicle towards much growth and personal development. This working-through process was also a critical mechanism by which healthy adjustment could occur, and meaning could be derived of the traumatic event.

Caregivers' need for professional guidance and support with respect to emoting was conveyed in countless ways. One caregiver explained, "I want to be able to vent with the [*], and get that support, and know she's always there for me." Another implicitly conveyed his need to express emotions by espousing: "I'm a very impatient and demanding person. I have to fight that in dealing with S." Yet another described the therapeutic effects of an empowering practitioner in this way, confessing,

And you know, when you talk about it in the open, it doesn't seem as bad as when you're thinking about it in your mind. And that's basically what [*] let me do: she let me talk about it, and ramble on. And get mad, and scream, and jump up and down.

This caregiver again underscored the importance of emoting, as she stated:

[*] is the daughter I didn't have. Between her and [*]-- I don't know who saved me the most! There again, [*] only got me through at crisis points, where [*] got me through pretty well every day... with my moods swings up or down. And she could settle me. But there again, there was just somebody else I could talk to, and sound off to. That's a good buddy system -- we didn't have a lot in common, but we had a lot we could talk about concerning the brain injury.
Yet another caregiver affirmed that a [*] was instrumental in assisting her daughter in dealing with her anger, thus invoking fundamental change in the availability of coping resources:

It wasn't until just about two and a half to three months ago that the children requested [*] support because they were having such a hard time dealing with their emotions. My daughter's been very verbal about how much she thinks of her [*], and how valuable she's been to her. She's a totally changed person in the home. Our relationship has improved because her anger is gone. She doesn't fly off the handle at little things anymore. My son is still quite quiet. He doesn't like discussing the accident because he was in it, and it brings back difficult memories.

But what is going on with the [*] being determined to be of benefit to him as well. In all such instances, one got the impression from caregivers that expressing one's emotions was incredibly therapeutic. Health care professionals who fostered an open, honest communication of feelings often facilitated a self-healing, cathartic process by which healthy adjustment could occur, and meaning could be made of the traumatic event.

The need for professional support further unmasked itself in descriptions that were replete with requests for assistance with the community re-entry phase. Specifically, there was a pivotal need for assistance in facilitating the transition of the injured family member from the hospital/institutional setting to the community re-entry/home setting. In one instance, a caregiver disclosed a health care professional's admonition that she would not be satisfied with the community re-integration phase of the rehabilitation process:
It was only when she [injured individual] was discharged that I had any contact with the [*]. And subsequent to that we have seen him for follow-up but... I don't know... my feeling about going there is that he's just updating his files. Like, I don't get any direction really from him. And when she was discharged from [*], he said to us, "You know, you're happy to be taking her home but, it's just like dropping you off the edge of a cliff. You're not going to be very happy with everything." You know, this was his prediction.

In view of caregivers' impressions that they and their brain-injured relatives were currently "being dropped off a cliff" following acute and post-acute rehabilitation, it was hardly surprising to learn that many caregivers had novel and innovative solutions to offer. As one woman put it, "I would have liked to have seen rehabilitation workers brought into the rehabilitation hospital prior to discharge so that it would be a smooth transfer back into the community." Another caregiver, in particular, argued quite passionately that to ensure a smooth transition from hospital to community, rehabilitation firms and their helping practitioners should "get into" the hospital:

They're [rehabilitation practitioners for private firms] going to have to get into the hospital settings, and get out into the community so that the transition from hospital to community is going to be a smooth one. Hospitals should make sure they pass on the information that there are rehabilitation companies out there that can make the transition back to the community a little easier, and that they should allow these workers to work along-side caregivers in the hospital prior to discharge, so that the family member doesn't have to start all over again once they
get back to the community.

Similarly, another recommended that a commitment to learning about available community resources, imparting that knowledge to clients, and educating the community about head injury should greatly improve the process of facilitating re-entry into the community:

Our thrust now is to community-based care, and this means that rehabilitation companies have a lot of work to do because they have to know each and every community that their clients are going back to so that they can tap the appropriate resources. And this is a big job. If the rehabilitation companies are going to do the job that they need to do -- then they've got to work both with the hospital and with head-injured individuals, so that these people have the quality of life they deserve!

And I think rehabilitation practitioners are responsible for learning what is out there in the community, and educating the community about brain injury resources to make sure that these people are actually made to feel comfortable and a part of that community.

Yet another argued the need for case management, and the need for active involvement of rehab firm for family at the hospital not only in the community re-entry phase:

That's the problem, just a little aside here: the rehab companies don't get involved until after the hospital stay, after they're out of the hospital in the community and dealing with their problems at home. So, maybe rehabilitation providers should be stationed more in the hospital.

Whereas some caregivers recommended that assistance be offered prior to hospital discharge, others recommended coaching immediately afterwards. Expectedly, caregivers
envisioned a rehabilitative system of care which teaches families how to properly deal with their injured relative. Accordingly, caregivers recommended that rehabilitation practitioners need to coach families through the community re-entry transition (i.e., strategies for management). In this respect, what is urgently needed is some form of ongoing professional follow-up at regular intervals. As the family's comfort, confidence, and competence increases, support is continued on a staggered basis only, until the family is progressively weaned off the professional emotional support completely. One caregiver pleaded that,

We need people who understand what brain injury is. [During the community re-entry phase], maybe even walk us ... walk us through it a couple of days with the patient. Not necessarily do it for us, but walk us through, coach us. Help us rephrase the way we've worded things. Um, very much like in this videotape -- it shows the wrong way to handle a patient, and then it shows the right way. There is so much to learn about head injury, rehabilitation, and strategies for management. And I think that would have been very helpful to have somebody with that brain injury knowledge at home with us at first.

Yet another stated,

Even if it was a [*] that we could go and visit [after hospital discharge]. Um, someone who is knowledgeable about brain injury, and its effects on the family...

You know, the [*] could set up an interview for the family to go and meet with a [*], and find out: What are some of the things that we can do to help a brain-injured person? A [*] probably would not come out to the home. But even if we
went in for a couple of appointments, as a family, prior to J. coming home. And then maybe later, once he is home, how are we making out? Set up three appointments over a span of, say, three months. Something like that! Because they're also seeing the way we're interacting as a family. And, maybe it could be an encouragement to the more quiet, inward family members. And give us some more strategies to encourage one another as well as be a support to J.

Another caregiver suggested that professionals be available to live with the family to assist them in coping in the transitionary phase:

I think it would even ... it might even be a suggestion to have someone come home with the patient for a couple of days, and say, you know, even live in. And, and... help the family cope with the re-entry process, whether that could be done through home... uh, through a [*], or through someone in [*] whose had some education in head trauma.

Yet another similarly recommended that practitioners link up to families during this important transitionary time, and argued the need for practitioners to support families when the injured family member re-enters the home:

I think I've talked a few minutes ago about the brain injury organization. There must be trained personnel in those organizations that could be a link with the family, just prior to the patient coming home, or after the patient comes home.

In line with the notion of community linkage or outreach assistance, another caregiver suggested the possibility of a referral network of service-providers whose aim is to refer families to needed services during transitionary times. As one caregiver explained, "I
would have loved to have had a referral, or a mention that perhaps a rehabilitation company would have been in order at that point. But, I didn't have it." Similarly, the need for greater direction by rehabilitation practitioners, during the community re-entry phase of the rehabilitation process, was again reiterated by another caregiver, who envisioned:

What I would like to see is, for instance, a [*] at [*] sit down with me and say, "All right as J. has re-entered the community, he is going to be going to a [*] centre. He is going to require these kinds of therapy. Your family might require an hour... you know, once a month for two or three months with a [*] to help you better understand the injury itself and how you can cope with it, and understand one another's reactions. Because your reactions are all going to be different.

As an additional means of facilitating adjustment to trauma, caregivers also recommended that there be allowances for home maintenance during this transitional phase. Advocacy or outreach initiatives on behalf of families might assist families with household tasks. As one caregiver suggested,

And so even if there's a volunteer group, locally, that does that kind of thing [home maintenance]. You know, get retirees or youth in the community, who would come and cut a lawn, or... or do some home repairs, or um ... . I don't know even whether there is a service like that available.

Amongst all of these descriptions, the common denominator was that families need assistance in ensuring a smoother transition to the community.

Another professional service that was heavily championed in this study, rather implicitly if not explicitly, was the need for family re-integration assistance. Due to
reported breakdowns in the family system and weakening of family bonds, there was a need for rehabilitation professionals to assist caregivers in reconstructing familial ties and relationships post-trauma. While one caregiver explained, "We need to learn how to be a family again," another reiterated, "The family has certainly grown apart [since the trauma]." Yet another caregiver expressed the disunification of the family in this way, stating:

I believe that both V., our daughter, and G., our son, would have benefitted from being able to speak to someone with an empathetic ear, other than parents. Because they were under a lot of stress to hide their problems from us because they could see we were under a lot of stress. And so the family members get into this vortex, this ever-narrowing circle of trying not to show the other family members the trauma they were suffering and trying to support their other family members. And of course, it gets to a stage where you begin to break apart. I believe if I could have said, "You're going to talk to this person," and they could have spoken to a stranger who understood what they were going through in some measure that they could have unburdened, and at least had a professional ear listen to them.

Another caregiver similarly shared,

But it wasn't a family ... for months. And then, when S. came home, and was so different, they [siblings of injured individual] didn't know how to respond to him. So, the whole family, the whole word family was just turned upside down. It was... we were dealing with so many changes ... so many appointments, so little
time in the home that you couldn't be a family.

Predictably, relationships were impoverished as a function of the significant stressors which generally accompany the onset of brain trauma. Strained, disintegrated family relationships were reflected in a multitude of descriptions. Some of these cast emphasis upon family members' impatience with the new personality of their brain-injured family member. Others betrayed a lack of acceptance of the injured member's self. Still others unravelled a lack of acceptance of various family members' unique grievance patterns, coping styles, and diverse growth rates in response to adjustment and loss. Regardless of the nature of the relationship tension, all adversely affected the quality of family ties. As one caregiver shared,

Much, much more talk than... [injured spouse] over-explains everything, over, over-explains everything. Um... constantly complains of headaches and difficult pains and uh... . You know, just basically, he's not (pauses) the happy-go-lucky person that he was. I wish he could just go back to the way he was.

Another caregiver similarly argued for the need for professionals to impart coping skills, teach the family how to adapt to the new family member, and teach them how to reinstate a relationship with the injured individual, confessing:

Our other children have to learn how to cope with S. because they had been very close. And now S. is a different person. They [other adult children] didn't know how to handle him or how to deal with his anger. And they still don't. And they're still in need of some sort of counselling. S. hasn't very much to talk about anymore. They just... they don't know how to talk to 'im or what to say to 'im, or
because they have nothing in common with him. They need to be able to realize that S.'s a different person, and to get to know him again. But how to go about doing that?

Another reiterated,

Now maybe had the insurance company been more cooperative, there might have been more of a transition because we would have had a program set up here. But there was no program and J. came home and all he did was sit and do jigsaw puzzles, by the hour, eight hours at a time. And that was difficult to cope with as a family. How do I help him? How do I stimulate him to do other things, without pushing him? And where are the limits? So there needs to be education, more education.

Another caregiver expressed the marital tension in her relationship with her injured spouse in this way:

I think G. is gettin' very ... . I don't know (sighs) if depressed would be the word I would use or not. He can get up every day and do the same thing. He gets up and he gets coffee at 9. Then I... we do our work. Then sometimes he goes off to nap. See that's nothing. I mean, you don't have repairs every single day. And I mean, the way he feels, he can't push himself to do things that need to be done.

So, as a result, he doesn't like to see me workin' all the time. But I'm the one who getting paid to do the work so I should be workin'. So that causes a little bit of friction. But if he had somethin' to do in the afternoon, like he was supposed to go out Friday and play (...)twice a week, um... even if he was gettin' out, for two
or three hours, do anything, I don't care what he does -- except walkin' around in malls. When he starts, it drives me crazy, I don't know why he does it. I can see me doing it, not him!

If there were a need for caregivers to learn how to strengthen family bonds, there was also a need for caregivers to learn how to deal with each other's unique grievance patterns, and accept the individual and diverse pace of growth rates in response to adjustment and loss.

I guess, if they're [uninjured sons] like I am, they would wake up and think everything would be fine one morning. And it's just... it's never gonna happen. It's not gonna happen. But I'd like to see them understand that, and know that for sure. They won't admit there is a greater problem. And that's the biggest problem, period. They will not admit for it. And they've got to learn, as I say, everything's not going to be OK. Everything's not going to be OK. And it's never gonna be OK again.

This particular caregiver's need for her sons to be more understanding, compassionate, and accepting of their injured family member's injury stemmed from her own need for validation:

My boys... I'd like to see them understand it better. They never talk about it. They don't want to talk about it. They don't want to realize there's such a dramatic change in their father... . It would make me feel better if my sons were able to show me they understand that there is a problem, and that their Dad is not going to wake up someday and be better. He's not.
And similarly, "I think it would help if they [uninjured sons] would realize why I get the way I get at times, when I'm so uptight and they won't do things for me. If they could just understand me."

Again,

There's a need for them [adult children] to realize that there is a big problem. But they... they won't realize it. They won't... they won't say, "Oh, my dad's had brain injury." They're very embarrassed about it. I really wish they could understand what is happening and how much more I've... (pauses) I don't want to say rely on them... or need them, but...

Or, "Well, it starts with the [*], in helping us understand each of our own individual feelings. And the [*] is also doing that. But then, how to integrate and understand each other's feelings?"

Alternatively,

I couldn't tell you the way either one of the boys feel about it. I couldn't even tell you ... ... I couldn't even begin. We just never ever, ever talk about it... . Help them understand and I think it would help... . Yeah, I think it would help the whole family life, you know... I don't know. I just feel if they understood, and knew there was a real problem... maybe they'd be a little more compassionate. Maybe even a little more understanding, maybe be more appreciative of their father.

In some instances, relationships were so strained, and the disintegration of family relationships so advanced, that individual family members were left grappling with their
own adjustment process in their own individual ways, without the benefit of a pooling of their own collective resources. One caregiver disclosed,

Well, I think, the family has not felt the same since the accident. We just haven't been a family. And that is about as far as I can explain it. I don't know what has happened. I have no idea. There's a discomfort with one another that wasn't there before [onset of injury]. Before, we were very close. We lived within one another's pockets all the time. But now there's a separateness. I guess we're all trying to deal with things ourselves. But there's a shifting, and it's not a comfortable feeling.

The need for family counselling was again indicated in the following descriptions:

And therefore the weeks go on and you keep saying, yes, we should really get help because we are having a problem with this [family relationships], and we can see each other coming apart at the seams." And then saying, "well, we'll go on for another week and we'll see how things go."

Or again,

I think it would help if there...if there was a little bit of family counselling. Umm.. I don't know if it would help for sure, but there would definitely be something to talk about. You know what I mean? Like, I don't know if my father [caregiver] would be accepting of it. But, he's kind of found a place to stay... a place to stand in terms of his acceptance of things, and I don't know if counselling would rock the waters but, I guess it could help.
Closely related to the need for assistance with the reintegration of family relationships was the necessity for help with role integration. Caregivers consistently envisioned a rehabilitative system that assisted them in dealing with the role reversals in their family relationships. The parent of a brain-injured individual shared:

P. and myself have moved from having been parents of little children who need guidance and care, to being the parents of adults who have hopefully learned and can now go out and try out for themselves. And that has been reversed again.

In another description, a full-time homemaker-turned-superintendent argued the need for ongoing family support of women whose spouses become brain-injured and who, therefore, find themselves suddenly thrust in an independent, self-sufficient, breadwinner role. According to this particular caregiver, there is a role for professionals at various stages of adjustment for "mature women of her generation whose spouses did everything for them." The need for educating mature women to assume greater independence, and help ease them with their role transition, was further implied in the following:

I think a lot of women, maybe not as much today, but in my generation -- their husbands did everything. So I think, you know, people in my age group need to be educated, depending upon what has happened to them. That's really important. I don't think you're going to find that in the young women today, like you would in my generation. We were brought up with the men, and they were the heads of the family (...) I think they should have different stages [levels of outreach assistance] for women. Like maybe seven months after the accident, and then extend it to a year, and then, you know, every two years. Have different stages so people don't
feel quite as alone.

**Informal Social Supports**

In as much as caregivers underscored the importance of professional supports in facilitating their adjustment to trauma, one cannot underestimate the importance of informal social support networks. Such networks represented vehicles by which families of the brain-injured obtained love, encouragement, support, and much needed courage. The sharing of real-life experience, information and resources, and common sense of purpose, brought a sense of belongingness and solidarity to caregivers that was otherwise less commonly embraced under the traditional umbrella of professional support.

Informal channels of support, underscoring the importance of friends, family, neighbours, religious affiliations, TBI family peer support, and the helpfulness of extending support to others in a similar predicament permeated caregivers' descriptions. One caregiver stated, "The support of family and friends I guess is the most helpful," while another mirrored, "We need the support of our friends and our family." And again, "I had thirteen friends show up [during intensive care] to support me, to be a moral support."

Still another caregiver confided,

I'm not very positive about the support given me at [*], and I think I couldn't have gotten through this if it hadn't been for family and friends. I mean, they were the only ones that kept saying, hey, you know, keep going.

Similarly, another volunteered:
We will now consider the effects of these changes on the overall system performance. The introduction of new variables and parameters has led to a more complex model, which may require additional computational resources. However, the benefits of increased accuracy and predictive power may outweigh the increased computational burden.

In the next section, we will discuss the implications of these findings for future research in the field. The results suggest that further exploration of these new variables could lead to significant improvements in our understanding of the system behavior.

Appendix A presents the detailed calculations used to derive the results presented in the main text. These calculations are available for download and further study by interested researchers.
And my daughter came and was a solace to me when I cried, instead of me trying to get her to, you know, open up more. She came and sat with me and put her arms around me, and was a tremendous support.

Yet another caregiver disclosed, "I certainly picked up the phone and just called different people. Not just professionals. But also friends, close friends, who knew, and you know, they could understand, and they were there for me." And again,

Immediately upon injury, if I take service as meaning support to me through family and friends, it was excellent. I have a really good social support network. And if I take it to mean that service given by rehab or, you know, professional service providers -- I'd say the quality of service wasn't that great, meaning that I didn't...

You know, maybe I'm blocking out a lot of this or maybe I'm not remembering everything. But, I don't ever recall being approached by any professional service provider.

Included in the definition of informal social supports were not only family, friends, and neighbours. No less important was faith and religious convictions. One caregiver, in particular, stated: "But I had a lot of support from friends and the pastor at the hospital," while someone else stressed the importance of faith, acknowledging: "I certainly was very, very upset inside. But I also have a strong faith." Another caregiver similarly shed light on the fact that, at least for her personally, the circle of help to families of the brain-injured goes beyond the professional realm, as she stated:

The chaplain, now it's interesting -- he was very helpful. I had tremendous back problems, and you could not get parked at the hospital. And I had to walk almost
a mile after I parked. And so, on my behalf, he went down to the parking director and explained the situation and, got me a reserved parking spot while I was at the hospital. So he was wonderful!

Technically, then, all of those who support the family, either directly or indirectly, may be considered to be a part of the overall umbrella of service-provision. In this way, even so-called indirect providers may nonetheless impact upon caregivers' overall impression of service-orientation.

Another inclusion in the umbrella of non-professional supports was TBI family peer supports. This refers to the support that families of the brain-injured received from one another. The general consensus amongst caregivers was that the benefits derived from such support were tremendous, so much so that most would have liked to have seen this facet of helping being incorporated into the gamut of rehabilitative service programming. As one caregiver explained,

I found education, I found support, by being among others whose family members have head injuries or who are head-injured, and I can better learn to deal with feelings and behaviour, and everything else that goes along with living with someone with a head injury.

Another confirmed,

But what you need... what I think you need there, at the hospital, for somebody like me, would be somebody who could just sit with you and have coffee, and let you babble on and on ... Because with professionals, you hold things back.

Another expressed, "I guess, in retrospect, that would have helped to be amongst my
"own," while someone else reiterated:

I believe that if we had been given an individual or a group of individuals to whom we could have gone as a family or as individuals, who could say, "Yes, here's what you are going through, here's what you are going to go through, here's what you're feeling, here's why you feel it, and here's what you can do about it." This would be helpful because of all of the unknowns in brain injury.

In line with other descriptions, another caregiver contended,

We need someone who's been there before. Like other families who have been in the same situation. Maybe they're willing to talk about their experiences. It might help us to adjust better, and they might be able to help solve problems. They've already been through the situation, and know how to handle it. And maybe not even necessarily a family. Perhaps even someone who has been very close to the kind of head injury that S. had, who's gone through it; someone who has seen it, been there, and done it (pauses) -- who has that specific knowledge.

The need for a TBI family peer support network was again revealed in this description:

But even then, like I talked to the caseworker, and different people, and it seemed that there should have been more, in regards to support. I don't know how we're going to get support for the family -- maybe a meeting, a group meeting say, where you meet in somebody's house, or... wherever. That's vital. Because that's the part that I ... I was missing. I find they're very beneficial ... to talk to people who have gone, you know, before you, because I didn't know half of what was going to come. You know, it was all trial and error, and it was really surprising at
some of M.'s reactions that I didn't know what to do with them a lot of the time. And then it certainly would've been nice to have mother, father, or family around.

Another relayed,

And maybe have a buddy system. Buddy system? OK. That's like a support group. And let's say you have two children and I have two children. Your husband's been injured. My husband's been injured. We have a lot in common.

OK, exchange phone numbers. If you have a problem, we call each other up, have you been through this? Do you know what to do? And just kind of compare notes. We'd know there would be a bridge that would come out of this probably. But at first you'd be kind of... you've got nothing to worry about. Like you didn't know each other before, and you're not going to judge each other. But you will be able to say, "Well, yeah, that happened. And I did it this way. And I thought it was a good idea. And, this may help you. If this doesn't work, try something else.

I think that's what I'd do." That to me... would've helped me.

The buddy-buddy system as this caregiver conceived it, would provide the necessary support and guidance, but would simultaneously meet the needs for independence, freedom, and respite, as implied in the following:

And then you know, maybe you go out one day and you think, well I'll sit with you for a couple of hours, while she goes out. Like, when we were very young, here's what we used to do: Two or three of us ... the girls used to get together. "I'll keep your kids for the day and you go shopping" -- Christmas and that... and we found it worked out very well. I think this type of thing should start at the time
that the patient goes for rehabilitation in the hospital. And maybe, you know, towards the time the patient is coming home because then you have experience, and you can really converse. And it won't be like one is already that much farther ahead than the other... See if there were somebody I could phone, "is this good for you or bad for you?", it might have been better for me. I don't say it would work for everybody -- it wouldn't -- because everybody's different.

Consistent with all stories, one got the impression that the importance of family peer supports lay in the value caregivers derived from first-hand, direct, and real-life experience, rather than indirect, theoretical knowledge of the subject. One caregiver, for instance, stressed:

I didn't talk to families who were goin' through what I was goin' through. I mean, I heard the professionals when they were telling me about things. I heard that. But I think my experience has taught that, you know, unless you've been there -- you can't walk your walk, you can't talk your talk, so to speak. I mean, even though, those are professionals and they're in your field, it's out of textbooks. But if you get a real life family, who's talking to you... And I think, again, I stress, that that's what was lacking for me. I didn't have that.

Others emphasized the sense of understanding and common ground upon which families of the brain-injured stood, affirming:

But it's another thing, when you have to live it! And I think that's ... that would go a lot further with me, you know, if I could sit down, and talk to somebody who had that experience. That's what was lacking.
Another appealed to the same argument, in relation to the helpfulness of the spousal support group:

We went in and it was just spouses, which was something really necessary. Because I had contact with people who were going through the same thing as I was going through, not somebody telling me what I was going to go through. Apart from offering support and encouragement, family peer supports offered a unique opportunity for the sharing of learning and insights, as stipulated in the following:

The one thing that I... one service that's not out there ...one need that's not being met would be... I think it would be good if there was a group where couples could go because I think it's good for S. to hear other head-injured people and their spouses talking. I think he gets a lot of insight through that. I think that would be really good.

Additionally, caregivers' sharing of similar experiences amongst themselves seemed to give them the necessary strength and courage to continue. In this way, such exchange represented an opportunity for solution-making: "The most support I got at the [*]'s was really from other parents who were there who were going through the same thing. And we would sit down and talk amongst ourselves, and try to sort out things."

In a few instances, caregivers extended support to other families who were undergoing a similar experience. In such cases, one got the sense that offering such help to others in a similar predicament was a means of self-healing and catharsis. One caregiver, in particular, affirmed: "And I want to take what I've learned from brain injury, and going through this experience with J., and be available to help others who are going
through trauma later on." In such instances, offering peer support seemed to offer much self-healing and catharsis that so often accompanies acts of giving and helping others.

Caregivers' need for meaning making of trauma was again reflected when another caregiver said:

My goal is to turn this tragedy into triumph, and then use it to help others. And, whether I become a driver, or whether I just comfort a grieving person, or go and sit with them in the hospital -- and encourage them and say, "I understand how you're feeling because I went through this."

Another revealed,

I know a lady at the church that we go to, so I could get a hold of this mother's name, and just say that we've gone... also gone through a head injury in our home, and if there's any way that she felt that she'd like an afternoon out that J. and I could both go over.

Once again, opportunities to help others proved to be very therapeutic:

I found that in my sharing, I was able to encourage a couple of other women that were there [hospital], and it was very helpful in particular to one mother of a young son, who had come down from [*], and knew no one. And I want to take what I've learned from brain injury, going through this experience with J., and be available to help others who are going through trauma later on. (...) I remember the lady from [*] was sitting alone beside her bed, as I happened to walk by the room; I didn't know what room her son was in. But she was crying. And she had nobody. So it allowed me then to go and comfort and support. And then I met
another young girl, out on the front step, and sort of... that not only gave an awareness that other families were in trauma -- but it allowed those families to link up when they were at visiting... go down and have a coffee together and chat, and they feel that they had a family at the hospital, not only on staff, but other people that were going through pain and would understand. I found that very helpful... the empathy for one another, the understanding... . I think being able to validate one another.

In summary, family peer supports represented an opportunity to identify with, and empathize with other families, thus contributing to personal growth and development.

**Systemic Issues**

A seventh theme, which unified all participating families in this study, and was of particular importance to six of the eight families, was systemic issues. Systemic issues relate to the broad, global issues that underlie the infrastructure of rehabilitative care. They are the fundamental philosophical pillars upon which the social structure rests.

Caregivers identified various elements in this infrastructure, including: (i) Accessibility (i.e., how accessible were the resources/services?); (ii) funding (i.e., what were the financial resources of clients? How accessible was funding of needed services? What is the insurance company's stance vis-a-vis the authorization of needed service - cooperative, guarded, uncooperative, hostile?); (iii) timeliness of service interventions (i.e., how promptly was service delivered? Were needed services delivered in due course?); (iv) overall current socio-political health care climate; and finally, (v) the need for seamless
Many of these facets of service delivery are highly related and intimately intertwined. By way of illustration, the question of access may be interrelated with funding constraints and timeliness of service delivery, all of which may in turn be connected with the current climate of crisis in which our system of health care finds itself. For all intents and purposes, I will treat each of these as distinct entities for ease of presentation.

By way of comparison to the theme of Practitioners' Disposition and Character Traits, and the sub-theme of "being there" which shared commonalities with its parent theme -- the theme of systemic issues was far broader in scope. Whereas "being there" was microscopic in scope since practitioners were there for caregivers -- the systemic issues were macroscopic since they referred to the actual substructure or social structures in place in the service of health care delivery. As such, the systemic issues touched upon, and embraced, every theme in this study, including: education; control; practitioners' disposition and character traits; practitioners' qualifications, professionalism, and competency issues; and the need for professional and non-professional support.

Accessibility refers to the ease with which stakeholders might access available resources and services. Issues relating to accessibility tap into the ways in which families were informed about needed resources, services, or rehabilitative treatment facilities. Many caregivers reported that they were informed of their rehabilitative treatment facilities, subsequent to hospitalization in the acute/trauma phase, and via their rehabilitation practitioners. One caregiver stated:
So we had no choice as to that move -- when the move occurred, and how it occurred. [*] recommended that the best place for us, was [*] because it was close to us, and also had a good record. So that was how we got that information. We went to [*], had an interview there, and set up for our son to go there... . Then, [*] said, "What's next?" And we said, "Well, what's next? We don't know what's happened." And so he said, "Look, there's a new organization that's started up." And that's how we got in touch with [next service-providers], [*].

Another caregiver reported accessing health care facilities via the organizations' referral sources and advertisement in the newspaper:

We found out just through... . It was actually all organized for us through the hospital. When S. went to [*], the [*] there told us which rehab hospitals were available for head injuries, and she said that he would be put into whichever one would take him first, and that we didn't have a choice. And there was quite a long waiting list for [*], so... she said we'd just have to go to [*]. And then at [*], they organized for S. to attend [*] and they also organized the caseworker. It was just done -- that was it. And... I think we heard about [*] through the newspaper. They had just opened, and we saw an item in the Toronto Star. So we kept that in mind, and used that.

Common to half of the stories was a perception of excellent accessibility, while the other half of the sample reported dissatisfaction with accessibility. On the positive end of the satisfaction continuum, one woman affirmed,
It [accessibility of services] was excellent! Absolutely excellent. At [*], there were posters all in the hall on J.'s floor in the Toronto unit. And in both hospitals, there was an invitation, a printed invitation, as well as a follow-up telephone call -- we had to RSVP -- to see if we would be attending a group session. The family education night, case conferences... all of that type of thing. So I found that, yes, accessibility was there.

Another caregiver described her satisfaction with the [brain injury support organization] in terms of their provision of information:

We have educational needs which I think [*] does an excellent job with. They have their library, people who volunteer, and people who work at the office. They also have guest speakers on various topics. And, I think those are -- depending on the speaker -- they're really good at meeting the needs of family.

Another interpreted accessibility to mean the degree of convenience to rehabilitative health care sites. In her description, she reported satisfaction with accessibility since helping professionals' informed her of the available services:

Oh definitely, the services were accessible! All the services that we used -- we always found them through [*]. She would come to meet us, and if there was need for any type of service, she made sure it was available to us, and she would always try to get as close as possible, which was not always possible. But there was always a taxi at our disposal, um... through our insurance company, who paid for it. We were allowed and, in fact, urged to use the cab because a lot of the time, parking was not available.
Still, others stated that accessibility to supplemental rehabilitative care for their injured family member was largely dependent upon their own self-directedness, resourcefulness, and self-initiation skills. Of this group of caregivers, a common complaint centred upon their need to locate service of their own initiative, without the benefit of a proactive sharing of information on the part of health care practitioners. In several of these descriptions, it became evident that the question of access was highly related to a caregiver’s sense of knowing what to ask for. Hence, as discussed within the themes of control and education, assertiveness and competency with obtaining information played a pivotal role in accessing appropriate treatment and care. As one woman explained,

That was through me making inquiries, and getting referrals through [*] and through [*]. You know, once I had made that move...well, and had them on board, the funding was the other issue. There was difficulty in getting the funding. Like I could access the needed services, but, if we didn't have funding that would be a different... a totally different story, if we didn't have funding. We would not have been able to access the services that we accessed.

Similarly, another caregiver reiterated,

I don't think that the services were very accessible. Like, to be accessible I think you'd have to know about them first. You know, know their names to look them up in the phone book. To be accessible, you have to be known first, and I didn't really know about what was going on. Umm... the services that I utilized ..the ones that I found were most helpful are the ones I just recently found ... like, four
years after the accident. I found out about them just through applying for work and, you know, it just so happens that I have a background in Psychology, and that I'm looking for a job and using my experience with A. as background for working in the head injury field. They seem to coincide and so, just by landing jobs in the head injury field, kind of by accident, not on purpose -- I found education, I found support by being among others who... whose family members have head injuries or who are head-injured. And I can, you know, better learn to deal with feelings and behaviour and everything else that goes along with living with someone with a head injury.

Or again,

I feel that it's very difficult to get the services, to find the services... first of all, to find the services and then to access the services. The services that I have received have been excellent, and I think that by virtue of me advocating and seeking them out and finding them and looking at it from the perspective of other families. If somebody was going through it tomorrow... if I were to know somebody who were to sustain an injury tomorrow, and if I were to give them any advice, it would be direction on where to access the services because if they don't go after it themselves, then I think it will be a much more difficult road for them, and nobody will come to them with the services.

Yet another mirrored,

I guess my issue isn't so much about what the quality of services received. It's really access to services. But, you're not asking about access. If... because there's
There's definitely a gap there, and in my mind it's access to services, or access to quality services.

The difficulties with accessing both funding and needed services was further reflected in this description:

But, as far as kind of, a blanket comment on how available were they... to access them, as we talked about before, was very difficult. It was tough first of all to identify them and then to... I guess to identify them was the big thing. And then to have them funded. Those were the two big things initially. But, once past those hurdles, the services were there.

With respect to funding issues, as the second systemic issue that lies at the heart of the rehabilitative care infrastructure, several caregivers attested to a need for the provision of financial assistance to those families in need. As one caregiver explained,

The second part should be the availability of financial - not that we needed it -- but I'm creating a structure. In the British way, there used to be called a bursar, a person who helped a family if they needed financial advice or help. And we were fortunate we weren't in that position. But, I think for some people, that may be needed.

In addition to the need for financial assistance for families in need, common to all stories was a belief that there was a need for the availability of funding to pay for family service. As one caregiver expressed, "There should be funding available to pay for any counselling that we needed. We regret that we didn't get permission to pursue counselling." Similarly, another caregiver underscored the need for financial assistance
and improved access to funding sources, as she recalled: "I guess what's been not so helpful but, it's a reality that has to be dealt with -- the rehab, the practitioners, the [*] -- it's the funding difficulties... You know, dragging me into the funding difficulties."

Similarly, another shared:

They started driving J. to therapy, but they had a lawyer on their board, and when the lawyer found out he had been in a car accident -- she nearly had a fit. She said, that's the responsibility of the insurance company to provide that [coverage for transportation]. So they cut him [injured spouse] off. But it's normally $25 a day to transport him by cab, if I don't do the driving. And I'm paying $1,000 a month for [*] services for the children out of my pocket. And my [*]'s bill... I pay her when the money comes in. She's just been wonderful. But the others like to be paid at the end of the month. They don't want to go through the insurance company. So, ... our cash flow has really been depleted, and I had to give up my car when J. was in the hospital because he had no income coming in except a very small income from the insurance company.

While others complained of difficulties accessing the funding for needed services, one particularly vocal caregiver placed the burden of responsibility squarely upon her insurance carrier. Because insurance providers are responsible for the appropriation of funds for cases involving workers' compensation, motor vehicle accidents, or traumatic brain injury, they wield tremendous power in the management of a case. As the carrier has full ownership and control over the appropriation of funds for the management of any given case, the insurance company may adopt a cooperative, guarded, uncooperative, or in
some instances even hostile stance, in regards to the appropriation of funds for treatment and care.

One particular caregiver generally perceived her insurance company as a gatekeeper to her injured family member's treatment and care. Especially important to her, and intimately related to others' perception for the need for greater access to funding, were numerous complaints of her insurance company's lack of cooperation. This caregiver divulged,

When J. was sent home from the hospital, I did not feel prepared with what to handle. And I think that's where a gap came in. Now that wasn't the fault of the hospital. It was partly the fault of the insurance company. [*] told me that it was the most difficult insurance case they had dealt with. And they would not provide any rehabilitation services until they had a diagnosis. And because of the brain hemorrhage, they couldn't get a diagnosis through any of the tests they had done, and therefore the insurance company said, "No, we will not provide" -- and it's part of the... the home... the phase back-home process that there be a link-up in the community with rehabilitation. But the insurance company was standing in our way, and were saying, "No, not until we have a diagnosis."

In another instance, this caregiver stated that the insurance company's failure to fund was directly affecting her injured family member's treatment and care, as well as that of her family's:

The gap was the insurance. What happened was I finally had to phone the superiors at the insurance company and threaten them. They said they would not
provide services of any kind until they had a diagnosis. And so, I had to phone and threaten that they had till 10:30 the following morning to get back with an answer, or I would be calling in my lawyer. Because it was affecting not only J.'s rehabilitation people, but the rehabilitation people that we needed personally -- it would have affected our [*], it would have affected [*] [home care services] -- which were services directly to the family. And so, um, I gave him about 12-14 hours. And it was 25 after 10 the next morning when he phoned, and said, "All right. We will go ahead until we get a diagnosis." And so we were able to get the services available in place, and I called [*] back. They made the link up with various services in our community.

She disclosed, in yet another example,

It took me seven-eight months before a step, we had a very high step, and J. couldn't get in and out the front door very easily. And I finally had to go ahead and put it in myself. A step and railing... before the insurance company would OK it. And yet, when the insurance man was here, he said, "Boy, this step's hard to get down!" You know, it was really quite interesting. And yet, he wouldn't OK it. So I finally went ahead and did it, and sent the bill in.

Another identified systemic issue that underlies the infrastructure of rehabilitative care, relates to the timeliness of service interventions. With respect to the degree of promptness with which service was delivered, the sample was split concerning expressed dissatisfaction or satisfaction with this aspect of service delivery. One caregiver stated, "I guess my spouse and I both felt that we could cope because it was almost a year and a half
since the accident." Another expressed,

By that time, I felt that I was able to handle everything pretty well. I didn't really need it [family service]. I was living here with S. and I felt like... we were over the worst of it. I guess at the beginning, my husband and myself didn't really know how to handle things. But then after about a year and three months or so, you come to terms with it a little bit.

While a few expressed being satisfied by the degree of expediency and timeliness of service at the trauma phase, most were dissatisfied. Although one satisfied caregiver was aware of the limited hospital resources and the need to share available resources amongst other families, she nonetheless remembered:

We did receive service immediately. And she [*] was very good in explaining what was going to happen to S., I guess, and what was available for him... She was the first person with whom we spoke. And she was able to tell us what to expect. And she didn't... she was so busy. You know, we didn't use very much of her, because it's a big hospital.

By comparison, other caregivers asserted a need for service, particularly at the outset of trauma. "Two meetings were set up: One was the initial... what they call the intake meeting, and that didn't happen for two weeks. So the first contact I had with the entire team was two weeks! It was approximately two weeks!" Another similarly reiterated a preference for earlier intervention:

Education helped me to cope. But as I say I wish it had come earlier on, not later. That's my problem: I mean, now I'm fine. But... two years ago, I wasn't. And I
wonder if it would have made a difference there. I don't know if it would've or not... And I'm unsure of exactly when the proper time would've been for education. But I feel it could've been offered a little earlier, because everything was done more so when G. got home.

Another said,

I guess the timing when you get it [help]... is very important. You know, counselling some people... I guess I'll stop using some people and start talking about myself here. Counselling... I probably wouldn't have been responsive to it immediately after. Like, if someone came the day after and started asking me about my feelings? Well, maybe it would have been helpful... It would have been helpful to have someone start asking about my feelings the day after. As far as education goes, it should be immediately after the trauma, and given to me in doses that were in respect to the stage I was at.

Encapsulated in this sub-theme, were the incognito messages that practitioners reportedly sent to caregivers regarding their busy schedules and work pressures. Due to funding constraints and the current climate of crisis which characterizes our health care system, it was hardly surprising to learn that caregivers often felt squeezed by time pressures and constraints:

It's what I say in my position in management, that we can either be customer-oriented or manufacturing-oriented. The services we experienced were manufacturing-oriented. They were oriented to the hospital with which they were linked. And therefore, a lot of the time, it was limited to, "You've got 20 minutes
This is a sample text for the purpose of demonstration. It contains a variety of sentences and paragraphs to illustrate the natural reading format. The content covers a range of topics and provides examples of how text can be structured and presented in a document. This text is designed to help users understand how to create and format documents in a clear and professional manner. It includes discussions on various subjects, explanations of concepts, and practical examples to aid in the development of effective writing and communication skills.
to talk" and "Is that all you want to say?" And off we go, with our books under our arm to the next family meeting. And so there was this production-line family meeting issue that went on.

Another caregiver reiterated,

Whereas when you're in the hospital, here's another thing - you don't feel that you want to ask questions because these people are hurried, they have schedules. You see the surreptitious glances at the watches. You know, you see this impatience to get on to the next person because there are three other families behind waiting.

Finally, another issue that underlies the infrastructure of rehabilitative care concerns the overall current socio-political health care climate. In explicit and implicit ways, caregivers conveyed a sense that quality of care was compromised due to funding constraints, shortage of qualified staff, etc. For instance, one caregiver specifically reported dissatisfaction with the quality of week-end [*] care at [*] and [*]. In order to contain costs, [*] were allegedly hired on a contract basis during week-ends. However, presumably because of the nature of their short-term involvement with the health care facility, such [*] were perceived as uncaring: "You see, there was a shortage of [*] at [*]. At [*], there was a shortage of [*]. They were using alot of [*] from the agencies, and they just wouldn't care. And they didn't give... ."

Additionally, most caregivers attested to a need for a more flexible system of rehabilitative care which was adept at accommodating to the unique circumstances of clients. Frequently, meetings were held routinely on a given day every month, the result being that if that particular day were inconvenient, caregivers would not be able to attend.
"I haven't been to a [brain injury support organization] meeting. Everything's on a Wednesday night. They seem to have a thing about Wednesday night, these groups." In other instances, the inflexibility centred on offering service in a given geographical location. If the location were inconvenient for caregivers, no other alternatives were offered in its place. One caregiver lamented,

And then when S. moved to [*], we had [*] there who said that she would provide family counselling. But that wasn't really... suitable because my daughter lives in Mississauga and works in Mississauga, and my son lives in Peterborough. And so, it just wasn't feasible for them to come to Toronto.

Finally, in line with the overall socio-political health care climate, caregivers reported a need for additional resources, and greater number of rehabilitation professionals at the hospitals, particularly at the onset of trauma:

Public education, for sure, is one way you can improve the quality of service. I think a lot of brain injuries occur because of collisions and accidents. We should have more service providers in place at the hospitals and intensive care units.

Lastly, common to all stories was a belief that there is a need for seamless service. Caregivers perceived the system of rehabilitative care to be characterized by a disunified, disjointed, and uncohesive system of service, as opposed to a holistic, interconnected, and highly cohesive one, characterized by continuity of care. To use a metaphor: If a quilt represents the total system of rehabilitative care, the threads are the rich diversity of individual service components, various service modalities, service-providers, and other players. These are the mortar which bind the piece together. Likewise, caregivers felt
that the threads of the various components of the system somehow did not mesh synchronistically together, the result being an ad hoc, hodge-podge, patchy, piece of work -- rather than a holistically-crafted, beautifully interconnected, synchronistic, and aesthetic one.

Five of the eight caregivers commonly visualized a system of rehabilitative care that comprehensively connected the various health care facilities consulted, the gamut of professional modalities, the various stages of the rehabilitation process altogether into some rubric of comprehensive and seamless service. Caregivers' descriptions of "disjointed, disunified service" related specifically to several elements, one of which was a need for seamless service between the various health care organizations, as caregivers navigated through the extensive gamut of service-providers and rehabilitation process. There was, allegedly, a need for a unifying, more connected form of treatment for comprehensive service for both brain-injured and family clients since caregivers reported difficulties in dealing with the transitional points in time as they journeyed throughout the various health care institutions.

A second element which embraced the need for seamless service was caregivers' perception of the importance of continuity of service with respect to the attending rehabilitation specialists. Caregivers often reported a lack of unified, seamless service with continuity of care: The frequent change of staff rotations were a common source of contention for them. Finally, the five caregivers, two of whom were particularly passionate about the need for seamless service, unanimously agreed that there was a need for a unified, "one-stop-shop" type of concept for families of the traumatically brain-
injured. Cited reasons for the adoption of a comprehensive, "one-stop-shopping" concept as a means of improving the overall quality of rehabilitative service included: a perception of increased productivity; time-efficiency; energy-efficiency, and a source of comfort/reassurance for family -- all of which are of paramount importance to individuals who have lowered energy reserves.
CHAPTER FIVE: SUMMARY OF FINDINGS, RECOMMENDATIONS, AND CONCLUSIONS

Introduction

This final chapter summarizes the study's findings. Additionally, it presents the study's recommendations in a concise, actionable format, and raises implications for both clinical and research practice.

The purpose of this qualitative research study was to foster an understanding of families of the brain-injured's perceptions concerning the degree of satisfaction with the quality of service received. Additionally, its aim was to identify whether or not there are any gaps in service provision, and solicit recommendations as to how to improve upon the overall quality of health care to the target population. Questionnaires and semi-structured, open-ended interviews with eight families resulted in a richer understanding of stakeholders' perceptions concerning the degree of satisfaction with the quality of service received.

Summary of Findings/Recommendations

During the semi-structured and open-ended interviews, all caregivers responded to ten research questions by drawing upon their personal experience and knowledge, as consumers of rehabilitative services. The following data represent a summary of findings/recommendations based on all interviews conducted with families of the brain-injured. Because the summary represents caregivers' comprehensive responses to all of the research questions, it is organized in bullet format, both for ease of presentation, and ease of implementation.
Finding 1 - Education as a Source of Reassurance and Comfort

Primary caregivers of families of the brain-injured reported that education is a paramount source of reassurance and comfort. Information served to both alleviate families' anxiety and frustration, and support them throughout their emotional adjustment and adaptation to trauma. The following specific recommendations were made concerning the need for additional education and informational resources:

• **Provision of regular updates and follow-ups.** Practitioners should continue to provide regular updates and follow-ups as to the status of caregivers' injured family members.

• **Provision of additional family preparation and education as a precursor to family coping.** To reduce learning via trial and error, health care facilities and rehabilitation practitioners should provide additional family preparation and education relating to: (i) the nature of brain injury and its effects upon the family; (ii) assistance in dealing with the changes in roles and relationships following brain trauma; and, (iii) the imparting of strategies to assist or encourage caregivers' injured family member with the recovery process. Such education would foster better coping skills, and thus reduce families' sense of isolation.

• **Improvements in both the quality and scope of educational materials and methods of delivery.** Improvements in both the quality and scope of educational materials and informational resources programs, methods of
instruction, and learning environment were also recommended:

i) educational materials - Due to the reported lack of knowledge regarding the availability of services, and the lack of written material provided about brain injury, caregivers recommended a resource directory or listing of all available services to facilitate access to needed services. Both the directory and literature relating to brain injury and its effects upon the family might be made available at the outset of trauma in the intensive care unit.

ii) methods of instruction - There is a greater need for clarity, and simplicity of language devoid of medical, technical jargon to ensure caregivers have properly understood the nature of the communication being imparted.

There is also a need for education to be imparted in a way that is commensurate with caregivers' level of understanding, critical thinking abilities, and personality style. Similarly, caregivers would like to see the imparting of information be commensurate with the family member's stage of recovery and adjustment process.

In order to deliver appropriate and relevant education, practitioners should impart information in a manner that is suitable to caregivers' optimal learning style (i.e., visual, auditory, kinaesthetic). To achieve the goal of relevancy, practitioners must be willing to perform needs analysis, and embrace opportunities to
customize information to each particular family.

There is reportedly a need for a more practical, hands-on, and holistic approach in educating families as to the nature of brain trauma, and how to deal with the injured family member. Caregivers felt it was important to adopt an approach that is relevant to real-life experience, rather than one which is purely theoretical.

Due to caregivers' perception that instruction was unfocused, non-specific, and vague, rehabilitation practitioners' method of instruction should be consistently characterized by concreteness, relevancy, and specificity of information (e.g., "Contact so and so at such and such place at such and such telephone number," as compared to, "counselling might be helpful for you").

In order to derive optimal benefit during family education sessions, families felt it would be helpful to "fit" with other learners. For this reason, learners should be comparable in terms of outcome, injury type, date of onset, etc. -- once again underscoring the importance of customization in family education initiatives.

iii) instructional techniques - To allow for the assimilation of complex information, caregivers would like to continue to see concrete brain models and instructional videotapes utilized, in addition to the visual presentation of information in a concise, point-form format.
iv) educational support - Since caregivers relayed a need for professionals to support them during educational sessions and assist them with chunking ongoing information into "chewable units" -- there is a role for rehabilitation practitioners to play in helping families sift through and integrate their learning. Such educational support might take the form of a representative who would be willing to "translate the medical jargon into plain English."

Alternatively, I believe it may involve a learning coach who is available for clarification of information and/or summary of learning.

v) learning environment - Given that family case conferences and family education evenings were considered helpful, these practices should be continued. In addition, some caregivers reported a preference for a warm, comfortable, home-like setting for learning, rather than a cold, austere, clinical one. Greater attention to a more informal, inviting learning environment might further improve stakeholders' satisfaction with service.

vi) advocacy - Caregivers asserted that there is additionally a need to increase advocacy initiatives on behalf of brain-injured individuals and their families. The raising of public and professional awareness about the nature of brain injury and its effects should facilitate the injured family member's community integration, and generally
reduce the social stigma of brain injury.

Furthermore, since insurance companies are the stakeholders of funding, and therefore the key to access of needed services, advocacy initiatives directed to this target population should result in greater cooperation with the coordination, approval, and execution of treatment plans. This in turn should serve to reduce caregiver stress.

Finding 2 - Guidance and Support as a Means of Assisting Caregivers to Deal with Loss of Control Issues

Given the sense of powerlessness and helplessness that often permeates the lives of families of the brain-injured following onset of injury, caregivers would like helping professionals to assume a more active role in guiding and supporting them and their families in dealing with the following, all of which support the need for counselling:

- **Provision of additional counselling.** Practitioners should provide additional counselling to assist caregivers in dealing with: (i) feelings of powerlessness, victimization, and entrapment in their life situation; (ii) issues of helplessness and despair resulting from uncertainty about, and concerns about the future, and; (iii) intense feelings of anger, sadness, resentment, frustration, and guilt, surrounding the onset of traumatic event and ensuing life circumstances. Practitioners might assist caregivers in
controlling and managing their emotional state.

Finding 3 - Assistance in Lessening Caregivers' Degree of Responsibility/Burden and help in Regaining Control over their lives

Given the tremendous responsibility, burden, and loss of freedom and independence engendered by brain trauma -- caregivers reported a need for help with regaining control over their lives:

- **Need for increased case management services.** Caregivers relayed a need for normalcy, and a return to the way things were. They desired to move on with life, and to become less programmed by rehabilitation practitioners, less scheduled, less intruded upon. Therefore, to reduce the degree of entrapment by rehabilitation practitioners' well-intentioned programming initiatives and relieve caregivers' sense of burden and stress, caregivers reported a need for increased case management services or advocacy assistance. The objective of case management should be to coordinate the various rehabilitation services and modalities, and structure time for families' leisure, entertainment, and rest activities.

- **Provision of assistance with respect to household responsibilities.** As a consequence of caregivers' perception of isolation in single-handedly managing the care of their family member plus the household responsibilities that were traditionally shared amongst various family members -- there is a need for physical help with household tasks/chores. Case
management services/advocacy initiatives should make the case for a homemaking service, where warranted. Alternatively, the case manager should advocate on behalf of the family, soliciting assistance for families of the brain-injured from interested volunteering organizations (i.e., driving the injured individual to various appointments, cooking, performing minor home repairs, etc.). The family advocate should also liaise with local youth or retiree associations as another potential pool of people who might serve to alleviate caregiver burden.

- **Provision of respite care.** Another reported stressor centred upon the onerous responsibility for caring for caregivers' injured family members. To restore caregivers' need for freedom and independence, and provide necessary relief of burden/responsibility, the necessity of respite care is highly indicated.

**Finding 4 - Assistance in Caregivers' Regaining Control over their lives via Skills Coaching in Self-help Strategies**

Caregivers expressed a desire for a more proactive, aggressive, and client-centred service-orientation in the provision of rehabilitative service. Specifically, caregivers advocated that a proactive rehabilitative service, characterized by suggestions, guidance, and referral to appropriate sources of help, would facilitate access to available information, resources, and services and, more importantly, lessen the onerous burden of care placed upon families.
• **Provision of education on self-empowerment, self-initiation, and other self-help strategies.** The overall consensus amongst the aggressive help seekers in the sample was that the health care system should assist families in gaining competency and resourcefulness in locating appropriate and needed information and services. I believe that the topic of personal responsibility should be discussed and promoted across family education programming. I also feel that self-empowerment, self-initiation, and self-directedness should be encouraged throughout the journey towards successful acceptance and adjustment. Moreover, for areas where there are defined service gaps, caregivers expressed a desire to have service-providers clearly delineate referral sources for families.

• **Delineation of service parameters and discussion of role expectations.** The rehabilitative system should proactively state the parameters of service at the outset of service provision, including clear delineation of professionals' role, clients' role, and descriptions relating to the service type, availability, and delivery. Rehabilitation facilities should establish the parameters concerning what they offer, as well as what clients can, and cannot, expect. A facility's self-assessment and open sharing with clients of their strengths and limitations was presumed to set the stage for clients' realistic expectations of service parameters, thus increasing the likelihood of greater overall satisfaction.
• **Adoption of strategies for more proactive, client-centred, and service-oriented service-delivery outcomes.** Because the majority of caregivers' lacked assertiveness, inner-resourcefulness, and self-directedness in learning how to access appropriate and needed services -- these families should have been guided regarding help-seeking behaviour, rather than invited to learn via trial by error learning. While I feel there is a need to instruct caregivers on self-empowerment and self-initiation skills with self-help strategies, there is also a dire need for health care facilities to be advised on various strategies for adopting a proactive and service-oriented approach to serving families' needs.

**Finding 5 - Practitioners' Disposition and Character Traits as a Means of Validating Caregivers' Sense of Value as Human Beings**

Of utmost importance to caregivers was a disposition and demeanour in their service providers which conveyed unconditional acceptance and a non-judgemental attitude. Such an attitude conveyed respect for caregivers' value and worth as individuals, and respect for the dignity of human life.

• **Conveyance of hope via a positive frame of reference.** Since the majority of caregivers felt that rehabilitation practitioners offered little hope, and were generally negative/pessimistic about the status of their injured family member -- professionals should be mindful to convey hope, reassurance, and encouragement to families of the brain-injured. A
positive, rather than negative frame of reference, in providing information and support, and greater attentiveness to practitioners' verbal and non-verbal cues, are recommended as a means of offering needed hope.

- **Conveyance of hope via enthusiasm and humour.** Another vehicle by which hope and encouragement was offered was through practitioners' enthusiasm and humour. Since enthusiasm and humour served to lift caregivers' compromised spirits and spread infectious energy, all efforts should be made to maintain and encourage this conduct throughout the helping professions.

- **Importance of a pleasant demeanour in service-delivery.** Caregivers appreciated practitioners who treated them with compassion and respect, and enjoyed practitioners with a warm, personable, and friendly disposition. Additionally, caregivers expressed being comforted by the warmth, encouragement, and empathy of rehabilitation practitioners. Professionals' caring and humanitarian approach was reflected in their overall willingness to offer help. Such gracious acts of compassion and kindness underscored helping professionals' respect, caring, sensitivity and compassion towards caregivers' feelings and needs. Additional virtues which were appreciated were patience, openess, and honesty.

- **The value of commitment, dedication, and an enabling, empowering manner.** Caregivers demonstrated an appreciation for highly committed practitioners who were dedicated to their work, and who demonstrated a
high degree of personal investment in their careers. They consistently appreciated generous-hearted and giving practitioners who were willing to go beyond the realm of duty, compared to those who did merely that which was required.

All helping practitioners of primary caregivers studied should strive to consistently model these aforementioned personal attributes. They should respect families, and treat them with sensitivity. Overall, an enabling and empowering manner was considered vital as a means of confirming caregivers' sense of value and worth as human beings.

**Finding 6 - The Character Trait of "Being There"**

"Being there" for caregivers was not only reflected in practitioners' physical availability and accessibility, but also through their communicated willingness to help. Overall, practitioners' response to caregivers was prompt, and attention to needs immediate. Especially appreciated were moments when practitioners' presence and attention were unsolicited. Such attentiveness and availability provided a sense of reassurance that families will not be abandoned, and allowed families to cope and adapt to the adjustment process.

- **Conveyance of availability.** As much as possible, practitioners should continue to convey a sense of availability.

- **Importance of dependability and reliability.** In a few exceptional cases, being there was not a significant and necessary condition for satisfaction.
In such cases, caregivers expressed dissatisfaction with occasional failures in following through on commitments, and some references to vague promises. As much as possible, rehabilitation practitioners should follow through on commitments to ensure a high degree of satisfaction with service delivery.

- **Use of a 24-hour distress hotline for families.** Although caregivers were generally quite satisfied with their rehabilitation professionals' availability, there were also some concerns expressed surrounding professionals' lack of availability outside of regular business hours. This finding therefore lends support to caregivers' recommendation for a 24-hour distress hotline for families. In addition to ensuring round-the-clock availability for families in their home cities, such telephone support is critical to those who find themselves in a state of crisis, while travelling outside of their home communities. Alternatively, in our age of the high tech information super-highway, information and support might be made available through either satellite telecommunications, or more cost-effectively, via the internet. A website could be installed at nominal fee, and a live, real-time chat session could be initiated with a roster of leading experts, caregivers, and/or brain-individuals in order to meet this particular need.
Finding 7 - Practitioners' Qualifications, Professionalism, and Competency Issues as a means of Conveying Courage, Hope, and Faith to Caregivers

Given caregivers' overall dissatisfaction with health care professionals' current state of knowledge and understanding of traumatic brain injury as a specialization, there is a need for improvements relating specifically to:

- **Degree of Professionalism.** There is a need for greater attentiveness on the part of the rehabilitation practitioners of caregivers studied in regards to appropriate professional conduct (i.e., reported shoddy execution of nursing practice; slandering of professional colleagues, etc.) Additionally, there is a dire need for greater accountability over rehabilitation outcomes. The consensus amongst caregivers was that practitioners should be held accountable and reliable for their actions.

- **Degree of Technical Proficiency/Competency.** Caregivers' demand for the increased competence of their particular rehabilitation practitioners stems from perceptions of an inadequate degree of knowledge and understanding of brain injury as a specialization. In view of this knowledge gap, the following recommendations were made by caregivers:

  i) need for a proliferation of professional training and education programs - To ensure a highly qualified and calibred body of professionals, there should be a proliferation of reputable professional training and education programs for professionals-in-training. There is, additionally, a need for standardization with
professional accreditation and training as a means of ensuring the availability of competent, well-qualified rehabilitation personnel.

ii) need for prospective practitioners-in-training programs - The education of practitioners should be characterized by a practical, hands-on experience. Clinical internships and practica should allow trainees to experience what it would feel like to live with the effects of brain injury. Through mandatory attendance at a transitional living centre or private residence, trainees would have the opportunity to get a feel for a day-in-the-life of brain-injured individuals and their families. The benefit of incorporating training in these environments is that it represents both an opportunity to observe clients in their naturalistic settings, and an opportunity to complement theoretical knowledge. Such knowledge is then presumed to increase practitioners' empathy and understanding of the experience of brain-injured individuals and their families, thus increasing their degree of effectiveness in helping.

iii) need for ongoing professional development of rehabilitation practitioners - In keeping with caregivers' request for more knowledgeable and competent practitioners in the field of brain injury, there is an ongoing need for professionals to be better educated about TBI. In this vein, practitioners should welcome regular and ongoing opportunities for professional development.
iv) understanding of family needs - Caregivers consistently stated that their rehabilitation practitioners need to better understand and respond to family needs. There is a need for additional recognition of the importance of understanding family needs.

v) Professional standards and regulations - To ensure a highly qualified and calibrated body of professionals, caregivers would like to see some type of regulatory, professional body in the traumatic brain injury rehabilitation field. This body would delineate, disseminate, and regulate the use of standards and guidelines for professional practice as a means of ensuring excellence and quality service provision.

- Human relations skills. Integral to helping professionals' competency with human relations skills is caregivers' satisfaction with professionals' ability to communicate, build rapport, and attend to caregivers. The crux of caregivers' perception of competency in this regard centred upon caregivers' satisfaction with practitioners' ability to express support, empathy, and understanding. Such expressions appeared vital as a means of conveying courage, hope, and faith to caregivers. Moreover, the effect of such attending behaviour was an indirect validation of caregivers' feelings and a sense of acceptance of being treated as individuals worthy of respect. Additionally, such skills conveyed a warm and safe therapeutic climate for client self-disclosure and growth. Despite caregivers' report of
overall satisfaction in this thematic cluster, some suggested areas of improvement nonetheless include:

i) need for additional probing to better ascertain caregiver needs - A few caregivers raised a distinction between listening and hearing, stating that they felt professionals managed overt issues well, but did not adequately address covert issues. Caregivers gleaned that to be more effective, practitioners need to probe in greater depth to extract the personal meaning that lies behind caregivers' statements or questions.

ii) need for further restating, rephrasing, and reiterating - Implicit in good communication and human relation skills is the ability to confirm that one's understanding is indeed accurate. Of those who expressed dissatisfaction, there is allegedly a need to make caregivers feel more heard, and thus a need for further restating, rephrasing, and reiterating as tools to facilitate clear communication.

iii) importance of an inviting and unintimidating environment characterized by an inter-dependent and reciprocal relationship with caregivers - To further facilitate rapport-building and comfortable feelings with practitioners, caregivers emphasized the importance of an inviting and unintimidating environment. Small talk should be initiated more frequently as practitioners open each client interview.
Most importantly, caregivers expressed a need for egalitarianism or shared power in their relationship with service providers. I believe helping professionals may communicate egalitarianism by their openness as well as willingness to establish an inter-dependent and reciprocal relationship with their clients. Such a relationship may be achieved via a collaborative, consultative process whereby both stakeholders engage in joint, shared decision making concerning rehabilitative treatment and care.

**Finding 8 - Lack of Family-Focused Service**

Overall, the caregivers studied were quite satisfied with the quality of care to their injured family members, but expressed unequivocable dissatisfaction with the lack of services for families, specifically. Repeatedly, caregivers expressed that they received only indirect support via their injured family members' service providers, and the majority often felt that they did not represent a valid treatment group in their own right. Indirect family support was nonetheless reported as cathartic since it had direct effects upon caregivers, and facilitated coping skills.

- **Ongoing need for dialogue with caregivers regarding service satisfaction levels.** Given caregivers' dissatisfaction with the quality and, in many cases simply lack of adequate family-centred service, and feelings of desertion and abandonment by both the system of rehabilitative health care, and the instruments of care -- there is an ongoing need to dialogue
with families of the brain-injured to obtain their input as to their degree of satisfaction with service, and to implement stakeholders' recommendations accordingly.

- **Maintenance of indirect family support via the health care providers of injured individuals, and espousal of more direct family support systems to caregivers.** Given the reported therapeutic effects of indirect family support upon caregivers, practitioners should continue, at the very least, to offer this assistance. At best, I believe they should plan, deliver, and evaluate on an ongoing basis more direct family support in order to improve consumer satisfaction substantially.

**Finding 9 - The Need for Professional Support as a means of Facilitating Adjustment to Trauma**

To improve the system of professional support for families of the brain-injured, caregivers envisioned the proliferation of a number of services, each of which is discussed below:

- **Case management services.** Anticipated expectations of increasing case management services is that such assistance would lift caregivers' onerous sense of responsibility.

- **Increased facilitation of coping skills.** The caregivers studied consistently reported a need for increased facilitation of coping skills as a means of fostering better adjustment to trauma. Caregivers specifically
expressed a need for rehabilitation practitioners to impart coping skills, and teach them how to adjust to, and deal with, their injured relatives. Of those who consulted psychologists, marriage counsellors, or social workers to help them better cope with their adjustment process, several underscored the rather dramatic contributions of these varied helping modalities in fostering coping strategies.

- **Professional guidance and support with respect to emoting.** There is also a demand for practitioners to help the family emote and deal with their feelings surrounding both the traumatic event and the ensuing life circumstances. The opportunity to emote appeared to be a calming, cathartic process by which inner peace and tranquility could be achieved. Emoting seemed to be a meaningful, enabling vehicle towards much growth and personal development. Health care professionals who fostered an open, honest communication of feelings often seemed to facilitate a self-healing, cathartic process by which healthy adjustment could occur, and meaning could be made of the traumatic event.

- **Assistance with managing the transition to the community re-entry phase.** While caregivers reported that there is a definite need for supplemental information about brain injury and its effects upon the family, there is a particular demand amongst caregivers for bridging the gap in education and support services at the community re-entry phase. In view
of caregivers' impressions that they and their brain-injured relatives are currently "being dropped off a cliff" following acute and post-acute rehabilitation, there is an urgent need for assistance in facilitating the transition of the injured family member from the hospital/institutional setting to the community re-entry/home setting:

i) active collaboration of rehabilitation personnel with other personnel within hospital setting - To ensure a smooth transition from hospital to community, caregivers recommended that their rehabilitation firms and helping practitioners get into the hospital, and collaborate with other hospital personnel prior to discharge.

ii) active commitment to learning about, and educating, both clients and the general public on available community resources - Caregivers in this study would like to see their rehabilitation practitioners actively committed to learning about available community resources. The process of facilitating re-entry into the community should be greatly improved by imparting that knowledge to clients, and educating the community about head injury.

iii) provision of family support to assist caregivers in coping with transitional phase - Practitioners should link up to families during this important transitional time, and need to support families with the injured family member prior to the injured individuals' return
home. Caregivers recommended that professionals or informal supports be available in the day to live with the family on-site for a specified period of time to assist them in coping during the transitionary phase.

iv) on-site coaching of caregivers throughout re-entry transition and provision of ongoing professional follow-up - Caregivers envisioned a rehabilitative system of care that teaches families how to properly deal with their injured relative. Health care professionals need to coach families through the community re-entry transition (i.e., strategies for management) following hospital discharge. What is urgently needed is some form of ongoing professional follow-up at regular intervals. As the family's comfort, confidence, and competence increases, caregivers felt that support should be continued on a staggered basis only, until the family is progressively weaned off the professional emotional support completely.

v) provision of community outreach assistance - In line with the notion of community linkage or outreach assistance, caregivers suggested the implementation of a referral network of service-providers whose aim is to refer families to needed services during transitionary times as an adjunct to on-site coaching.

vi) provision of homemaker assistance during community re-entry
transitional phase - As an additional means of facilitating adjustment to trauma, caregivers also recommended that there be allowances for home maintenance during this transitional phase. Advocacy or outreach initiatives on behalf of families might assist families with household tasks (i.e., youth, retirees, or other willing participants should be included within a respite registry, and invited to participate on an as-needed basis).

- **Assistance with family re-integration services.** Caregivers felt that their rehabilitation practitioners should offer family re-integration services consisting of the need for additional assistance with the re-building and strengthening of family relationships, and role re-integration. Due to reported breakdowns in the family system and weakening of family bonds, there is a need for rehabilitation professionals to provide additional assistance to caregivers in reconstructing familial ties and relationships post-trauma.

  i) assistance in strengthening family relationships - Caregivers felt that their practitioners should teach caregivers' families how to strengthen family bonds, adapt to the new family member, and reinstate a relationship with the injured individual. The focus of such facilitation should be on family members' impatience with the new personality of their brain-injured family member, and the lack of acceptance of the injured member's self.
the fostering of acceptance for family members' unique grievance patterns, and the facilitation of intra-family support - Caregivers welcomed opportunities for their practitioners to facilitate the acceptance of various family members' unique grievance patterns, coping styles, and diverse growth rates in response to adjustment and loss. In most instances, relationships were so strained, and the disintegration of family relationships so advanced, that individual family members were left grappling with their own adjustment process in their own individual ways, without the benefit of a pooling of their own collective coping resources.

iii) Assistance with role integration - There is also a necessity for professional help with role integration. Caregivers consistently envisioned a rehabilitative system that assisted them in dealing with the role reversals in their family relationships.

**Finding 10 - The Need for Informal Support Networks as a means of Facilitating Adjustment to Trauma**

In as much as caregivers underscored the importance of professional support in facilitating their adjustment to trauma, they cannot overestimate enough the importance of informal social support networks.
• **Family, friends, and neighbours.** Tremendous benefits were gained from the power of these informal supports. Such networks represented vehicles by which families of the brain-injured obtained love, encouragement, support, and much needed courage. The sharing of real-life experience, information and resources, and common sense of purpose, brought a sense of belongingness and solidarity to caregivers that was otherwise less commonly embraced under the traditional umbrella of professional support.

i) promulgation of the importance of informal supports - I believe that helping professionals should promulgate the importance of an informal support system in promoting healthy adjustment to trauma.

ii) assurance that adequate caregiver supports are well established - I also believe that professionals should assist interested families in ensuring that the necessary supports are in place throughout the entire course of the adjustment phase, and most importantly, at the outset of trauma.

• **Religious affiliations.** Because of the reported benefits of faith and religious beliefs in coping with the traumatic event and resulting life stressors, continued efforts should be maintained to offer chaplin services.

• **Service Environment.** All of those who support the family, either directly or indirectly, may technically be included in the definition of "service". As caregivers perceptively noted, even so-called indirect service-providers may nonetheless impact significantly upon caregivers' overall impression of
service-orientation. Therefore, it is vital that health care facilities recognize the impact of the overall service environment upon stakeholders' level of satisfaction.

- **TBI family peer supports.** With respect to the support that families of the brain-injured received from one another -- the general consensus amongst caregivers was that the benefits derived from such support were tremendous. These included but were not limited to: the value caregivers derived from first-hand, direct, and real-life experience, (rather than indirect, theoretical knowledge of the subject); a sense of empathy, understanding, and validation, derived from commonality of purpose; the promise of ongoing support and encouragement; and a unique opportunity for the sharing of learning and insights. Overall, family peer supports served as a meaningful, cost-effective vehicle for the sharing of information, knowledge, resources, and support from those who have "been there" to families undergoing trauma.

i) incorporation of TBI family supports into the gamut of rehabilitation service programming - Caregivers felt that TBI family supports should be incorporated into the gamut of rehabilitative service programming through the implementation of a structured, systematic type of buddy-buddy system. The consensus was that rehabilitation practitioners are in a good position to coordinate informal supports on behalf of the brain-injured and their families.
Caregivers recommended both face-to-face meetings and telephone support on an as-needed basis.

Two types of implementation were recommended: One involves the pairing of two caregivers, matched by stage in the adjustment process. It is critical that the pairing of buddies be well-timed so learning occurs as real-life experience is unravelling, not after the fact. The second type of implementation involves a more senior buddy who is willing to guide and support his/her more inexperienced cohort.

- **The supporting of caregivers who wish to support their peers.** In a few instances, caregivers extended support to other families who were undergoing a similar experience. Given that offering peer support seemed to offer much self-healing and catharsis that so often accompanies acts of giving and helping others, I believe that practitioners should take advantage of such opportunities for client meaning-making, personal growth, and development.

i) welcoming opportunities for caregivers to support other peer families - Rehabilitation practitioners should welcome all opportunities, be it professional or informal service-provision, to identify with, and empathize with other families. For those who are interested in acting as buddies/supports, practitioners should offer them an opportunity to be a support to others.
Finding 11 - Systemic Issues

Systemic issues relate to the broad, global issues that underlie the infrastructure of rehabilitative care. Owing to the breadth and complexity of systemic issues, it is important to note that the strength of caregivers' contribution in this specific area lies in the raising of many insightful comments, rather than in the recommendations generated necessarily. Bearing this in mind, as the fundamental philosophical pillars upon which the social structure rests, caregivers recommended that there is a need for improvements in the following areas:

- **Access difficulties.** Given caregivers' reported difficulties with accessing services, health care practitioners should improve accessibility to needed resources, services, and rehabilitative facilities. In this vein, caregivers recommended that practitioners increase public awareness initiatives, publish resource directories which list available services for brain-injured individuals and their families, (contact name, telephone number, brief description of service), distribute these at the outset of trauma, and train professionals to better assess and understand caregiver needs.

  Alternatively, access difficulties were envisioned according to the degree of difficulty of accessing rehabilitative health care sites. I believe that inconvenience in accessing the geographical location of service provides an outstanding opportunity for the use of satellite telecommunications, or the internet.
**Access to funding.** Given reported difficulties with accessing the funding for needed services, I feel that there is a dire need for the availability of funding to pay for family service, and provision of financial assistance to those families in need. In the face of our current health care crisis, no specific recommendations were made concerning solutions to the above-mentioned challenge. However, I believe that there is a definite need to explore innovative ways of obtaining funding for needed services.

Under current legislation, insurance providers are responsible for the appropriation of funds for cases involving workers' compensation, motor vehicle accidents, or traumatic brain injury. Because insurance companies wield tremendous power in the management of a case, caregivers recommended educating insurance company providers on brain injury in the hopes of obtaining their endorsement. Additionally, caregivers felt that aggressive lobbying and campaigning initiatives on behalf of the brain-injured and their families should serve to increase public awareness, which may in turn affect the availability of funds.

**Improvements in timeliness of service interventions.** It is imperative that support services and education be made consistently and expeditiously available at the outset of trauma. It may be helpful at this time to implement the buddy-buddy system when the need seems to be greatest. All other strategies and interventions in the service of rehabilitative treatment and care must be implemented at the appropriate time.
Counselling and family support services should increase particularly during the community re-entry phase, while education should be made on an ongoing basis.

- **Need for greater systemic flexibility.** Finally, most caregivers attested to a need for a more flexible system of rehabilitative care that is adept at accommodating to the unique circumstances of clients. Frequently, meetings were held routinely on a given day every month, the result being that if that particular day were inconvenient, caregivers would not be able to attend. In line with the overall socio-political health care climate, caregivers reported a need for additional resources, and a greater number of rehabilitation professionals at the hospitals, particularly at the onset of trauma. To meet this need for increased manpower in a time of fiscal restraint, I feel it is advisable to exploit the wealth of available resources on the internet, and the tremendous power of informal supports.

**Conclusion**

The purpose of this qualitative research study was fourfold. First, the study endeavoured to obtain verbal information from families of the brain-injured regarding their degree of satisfaction with the quality of existing service. In this regard, its aim was to foster an understanding of current satisfaction levels with a view to identifying whether or not there were any perceived gaps in the delivery of service. Second, this piece of research increased understanding of the target population's unique family needs, which
might in turn be incorporated into a future education programme for families of the brain-injured or otherwise assist educational planners and administrators in improved service delivery. Third, the study, endeavoured to obtain recommendations from family members as to how to improve the quality of service. These recommendations might in turn be incorporated into a future programme based on related current family needs. Four, the study aimed to determine what, if any, discrepancies exist in the perceptions of family members regarding satisfaction with quality of service. In this regard, the research may hopefully act as a catalyst in assisting family members to better cope with traumatic brain injury. It may furthermore provide rehabilitation practitioners and policymakers with a renewed understanding of families' current needs, and, therefore, act as a catalyst in improving the quality of health care/service delivery to this target population.

Given that family changes incurred as a result of brain injury can be severe, functionally significant, and prolonged, it is my hope that this work, along with similar contributions, will fuel the impetus for much-needed improvements in service-delivery. On behalf of all the caregivers studied who are the subject of this research study, their families, and the rehabilitation practitioners who serve them -- it is my sincere hope that the future holds much hope and promise for a more proven system of rehabilitative treatment and care.
The document contains text discussing the relationship between domestic and international economics. It mentions the importance of understanding economic policies and their impact on global markets. The text also refers to the role of international organizations in facilitating trade and cooperation among countries. However, the specific details and context of the discussion are not clearly visible in the image provided.
REFERENCES


Rehabilitation, 7(3), 94-108.


If the above statements are to be believed, it seems that the

theoretical framework developed in previous studies

and refined in the present work is consistent with the

empirical evidence gathered in this study. The results

suggest that the proposed model can be applied to

real-world situations and may provide valuable

insights into the complex interplay between

economic, social, and political factors. Further

research is needed to confirm these findings and

explore the implications of this model in different

contexts. However, the preliminary evidence

presented here is encouraging and supports the

hypotheses tested in this study.


Graduate Department, St. Catharines, Ontario.


Physical Medicine & Rehabilitation, 72(7), 460-4.


Appendix A

Outline of Research Proposal

Ms. Annik Moyal-Waldman
[Address]

April 10, 1995

[Addressees]

Re: Outline of Research Proposal, M.Ed. Thesis

Dear [Name of contact],

Further to our initial discussion in March '95, I would like to thank you for your invitation to submit an outline of my research proposal, in partial fulfillment of my Master of Education degree requirements. I am pleased to advise that my research proposal has now been approved and accepted by both the thesis committee and the Standing Subcommittee on Research with Human Participants of Brock University, St. Catharines, Ontario. With this in mind, I would now like to approach your organization, as well-recognized specialists in the field of traumatic brain injury, and experts in service provision to families of the brain-injured, in the hopes of attracting your interest in supporting this research by working together in recruiting a participant sample.

I know that [name of organization] has earned an excellent reputation in servicing those living with the effects of traumatic brain injury. I would very much like to work with your organization in furthering our understanding and development of brain injury rehabilitation, and welcome the opportunity to obtain your permission to recruit clients for participation in the research. Please find enclosed copies of pre-consent and consent forms, as per your request. These outline the research methodology in detail.

Once you have expressed further interest in the project, I would be pleased to submit to you a full copy of the research proposal, including instrumentation (i.e., Family Participant Questionnaire, and Family Interview Guide). You will notice that the actual proposal has been written in the past tense as though it were already completed, according to my committee's wishes. However, it is still a research proposal, and family participants have neither been selected nor contacted.

I trust this meets with your satisfaction. As you can appreciate, I am under considerable time constraints, and hope to be in a position to advise my committee of recruitment plans at my earliest convenience. Accordingly, I would very much appreciate your feedback as soon as possible. If you have any questions or concerns, please feel free to contact me at my home office at [telephone number]. I look forward to the pleasure of working with you to mutual benefit, and thank you in advance for your review and consideration!

Sincerely,

Annik Moyal-Waldman

cc: Dr. R.T. Boak - Dean of the Faculty of Education, Graduate Studies, & Academic Supervisor
Encls. Pre-Consent & Consent Forms
Outline of Research Proposal, M.Ed. Thesis

Title of Research Project: Families of the Traumatically Brain-injured: A Case Study Approach to Perceptions of Quality of Service, Degree of Satisfaction, and Family Needs

Researcher: Ms. Annik Moyal-Waldman, B.A. (Hons.), Psychology/Philosophy M.Ed. Graduate Student [Telephone number]

Academic Supervisor: Dr. R. Terrance Boak, B.Sc, B.Ed, M.Ed., P.hD. Dean of the Faculty of Education, Graduate Studies [Telephone number]

Background and Purpose of Research:
Briefly, I am conducting a qualitative research study under the supervision of Dr. Terrance Boak, Dean of Graduate Studies, Faculty of Education, at Brock University. I am interested in learning about families of brain-injured individuals. The intent of this study is to foster an understanding of the rehabilitation counselling practice of families of the brain-injured. Its purpose is two-fold. Firstly, I would like to learn about incumbents’ perceptions, concerning the degree of satisfaction with the quality of family services received. In addition to fostering an understanding of current satisfaction levels, my second aim is to obtain family members’ recommendations for a future program based on related and current family needs.

Participants:
As far as the number of people participating in the research is concerned, I am looking to interview 1-2 primary caregivers of 6 families who are: 18 years of age & over, whose brain-injured family member is in the community re-entry phase of rehabilitation, and resides in the same residence as his/her primary caregivers. I additionally wish to interview family members whose brain-injured relative has a significant (rather than mild or moderate) level of disability/level of social displacement, and who has sustained a traumatic brain injury, rather than an acquired brain injury. Informants should be reasonably articulate in English, able to provide consent, available for the entire duration of the data collection and analysis period (May-August).

Methodology/Procedures:
The first meeting with participants will consist of 1 hour, and will include a reiteration of my research purpose, a clarification of any outstanding questions/concerns participants may have; an opportunity to obtain consent; and, lastly, questionnaire administration. The second interview of 1-1 1/2 hours in duration, will invite participants to respond to the research questions outlined in the research proposal, as indicated in the following:

1. Tell me about your feelings regarding the quality of family services you have received. How satisfied are you with the family service you have received? What, if any, gaps are there in the delivery of service?
2. What are your family's current needs, if any, following the traumatic brain injury of your loved one?
3. What are your recommendations as to how to improve the quality of service to families of the brain-injured? How might rehabilitation practitioners incorporate these into a future program for families of the brain-injured?

In conclusion, I would like to emphasize that this research study is not an evaluation of service, but a description of family members' perceptions regarding the quality of family services received either at the facility in question, or elsewhere.
**Family Pre-Consent Form**

**Title of Research Project:** *Families of the Traumatically Brain-injured: A Case Study Approach to Perceptions of Quality of Service, Degree of Satisfaction, and Family Needs*

**Researcher:** Ms. Annik Moyal-Waldman, B.A. (Hons.), Psychology/Philosophy M.Ed. Graduate Student
[Telephone number]

**Academic Supervisor:** Dr. R. Terrance Boak, B.Sc, B.Ed, M.Ed., P.hD.
Dean of the Faculty of Education, Graduate Studies
[Telephone number]

**Background and Purpose of Research:**

Hi! My name is Annik Moyal-Waldman. I am a graduate student in the Faculty of Education at Brock University. In partial fulfillment of my degree requirements, I am conducting a research study under the supervision of Dr. Terrance Boak. I am interested in learning about families of brain-injured individuals. The intent of this study is to foster an understanding of the rehabilitation counselling practice of families of the brain-injured. Its purpose is two-fold. Firstly, I would like to learn about your perceptions concerning the degree of satisfaction with the quality of family service you received. In addition to fostering an understanding of current satisfaction levels, my second aim is to obtain your recommendations for a future program based on related and current family needs.

**Procedure:**

If you agree to participate in this study, I will first meet with you and your relative to personally assure you of anonymity and confidentiality. At this time, I will briefly reiterate the nature of the research, its purpose, and procedures, as well as respond to any questions or concerns you may have. In the same meeting, I will request that you complete a brief questionnaire, administered by myself. The questionnaire should take no longer than 10-15 minutes. In the questionnaire, I will ask you to tell me about who you are, and a bit about your family also.

In the second private interview, we will meet at a time and location chosen by you for approximately 1 hour. I will meet with your relative privately at another time. At this session, I will ask you about your feelings regarding the quality of family services received, as well as your satisfaction with such service, and whether or not there were any gaps in the delivery of service. I will then ask you about your family's needs, and the means by which these might be incorporated into a future program for families of the brain-injured.

Lastly, I will provide you with a typed copy of the transcript of your previous interview, and ask you for any input/comments/feedback. It is my opportunity to check that I have correctly heard and understood everything that you have said. It is also your opportunity to re-read the transcript, to correct or change anything you have stated. If there are any changes at all, I will happily update your transcript accordingly.

**Benefits:**

Information gained from the study will help rehabilitation practitioners better understand the needs of families of the brain-injured. It may therefore also improve the overall quality of health care to families of the brain-injured.

.../...
Confidentiality:

I want to assure you of utmost confidentiality and anonymity. All information that is gathered, be it through questionnaire or private interview, will be utilized for the sole and exclusive purpose of this research study. With your permission, I will tape-record the interview to be sure I can recall all that you tell me. Recorded tapes will be destroyed upon completion of this study.

Because your participation in this study is entirely voluntary, you will have the option, at any time, to withdraw without any penalty. I would like to invite you to contact me at [telephone number] should you have any questions or concerns, now, or in the future. Alternatively, you may contact Dr. Terrance Boak, Dean of the Faculty of Education, Academic Supervisor, at Brock University, St. Catharines, (telephone number). We will be happy to discuss them with you, and thank you for your time and consideration.

Sincerely,

Annik Moyal-Waldman
Annik Moyal-Waldman, M.Ed. Graduate Student
Family Consent Form

Title of Research Project: Families of the Traumatically Brain-injured: A Case Study Approach to Perceptions of Quality of Service, Degree of Satisfaction, and Family Needs

Researcher: Ms. Annik Moyal-Waldman, B.A. (Hons.), Psychology/Philosophy M.Ed. Graduate Student

Academic Supervisor: Dr. R. Terrance Boak, B.Sc, B.Ed, M.Ed., P.hD. Dean of the Faculty of Education, Graduate Studies

I, ____________________________, acknowledge that the research procedures described on the attached form and of which I have a copy, have been explained to me and that any questions that I have asked have been answered to my satisfaction. I also understand that there are no anticipated risks or any direct benefits for me or my family as a result of my participation in this research study. I understand that I am free to ask now, or in the future, any questions/concerns I may have about the study or the research procedures. Moreover, I have been assured that records relating to me/my family will be kept confidential, and that no information will be released or printed that would disclose personal identity without my permission.

With respect to both the initial interview and the subsequent private interview, I reserve the right to withdraw from the study at any time and without penalty. I further understand that if I do not participate in this study, or if I withdraw from it at any time and for whatever reason, that the quality of rehabilitative care my family receives will not be compromised in any way.

I hereby consent to participate.

__________________________________________________________________________  ____________________________
Name (Print)                                                                 Date

__________________________________________________________________________
Signature of Participant

__________________________________________________________________________
Signature of Witness

__________________________________________________________________________
Signature of Researcher

I am additionally aware that a tape recorder will be used during the second interview session, and that the recorded tape will be destroyed once the project is completed. I authorize the researcher to tape record the private interview, as indicated below.

Authorization to utilize tape-recorder: Yes ______  No ______
### Family Pre-Consent Form

**Title of Research Project:** Families of the Traumatically Brain-injured: A Case Study Approach to Perceptions of Quality of Service, Degree of Satisfaction, and Family Needs

**Researcher:** Ms. Annik Moyal-Waldman, B.A. (Hons.), Psychology/Philosophy M.Ed. Graduate Student

**Academic Supervisor:** Dr. R. Terrance Boak, B.Sc, B.Ed, M.Ed., P.hD. Dean of the Faculty of Education, Graduate Studies

**Background and Purpose of Research:**

Hi! My name is Annik Moyal-Waldman. I am a graduate student in the Faculty of Education at Brock University. In partial fulfillment of my degree requirements, I am conducting a research study under the supervision of Dr. Terrance Boak. I am interested in learning about families of brain-injured individuals. The intent of this study is to foster an understanding of the rehabilitation counselling practice of families of the brain-injured. Its purpose is two-fold. Firstly, I would like to learn about your perceptions concerning the degree of satisfaction with the quality of family service you received. In addition to fostering an understanding of current satisfaction levels, my second aim is to obtain your recommendations for a future program based on related and current family needs.

**Procedure:**

If you agree to participate in this study, I will first meet with you and your relative to personally assure you of anonymity and confidentiality. At this time, I will briefly reiterate the nature of the research, its purpose, and procedures, as well as respond to any questions or concerns you may have. In the same meeting, I will request that you complete a brief questionnaire, administered by myself. The questionnaire should take no longer than 10-15 minutes. In the questionnaire, I will ask you to tell me about who you are, and a bit about your family also.

In the second private interview, we will meet at a time and location chosen by you for approximately 1 hour. I will meet with your relative privately at another time. At this session, I will ask you about your feelings regarding the quality of family services received, as well as your satisfaction with such service, and whether or not there were any gaps in the delivery of service. I will then ask you about your family's needs, and the means by which these might be incorporated into a future program for families of the brain-injured.

Lastly, I will provide you with a typed copy of the transcript of your previous interview, and ask you for any input/comments/feedback. It is my opportunity to check that I have correctly heard and understood everything that you have said. It is also your opportunity to re-read the transcript, to correct or change anything you have stated. If there are any changes at all, I will happily update your transcript accordingly.

**Benefits:**

Information gained from the study will help rehabilitation practitioners better understand the needs of families of the brain-injured. It may therefore also improve the overall quality of health care to families of the brain-injured.
Confidentiality:

I want to assure you of utmost confidentiality and anonymity. All information that is gathered, be it through questionnaire or private interview, will be utilized for the sole and exclusive purpose of this research study. With your permission, I will tape-record the interview to be sure I can recall all that you tell me. Recorded tapes will be destroyed upon completion of this study.

Because your participation in this study is entirely voluntary, you will have the option, at any time, to withdraw without any penalty. I would like to invite you to contact me at [telephone number] should you have any questions or concerns, now, or in the future. Alternatively, you may contact Dr. Terrance Boak, Dean of the Faculty of Education, Academic Supervisor, at Brock University, St. Catharines, (telephone number). We will be happy to discuss them with you, and thank you for your time and consideration.

Sincerely,

Annik Moyal-Waldman
Annik Moyal-Waldman, M.Ed. Graduate Student
Appendix C

Family Consent Form

Title of Research Project: Families of the Traumatically Brain-injured: A Case Study Approach to Perceptions of Quality of Service, Degree of Satisfaction, and Family Needs

Researcher: Ms. Annik Moyal-Waldman, B.A. (Hons.), Psychology/Philosophy M.Ed. Graduate Student

Academic Supervisor: Dr. R. Terrance Boak, B.Sc, B.Ed, M.Ed., P.hD. Dean of the Faculty of Education, Graduate Studies

I, ____________________________, acknowledge that the research procedures described on the attached form and of which I have a copy, have been explained to me and that any questions that I have asked have been answered to my satisfaction. I also understand that there are no anticipated risks or any direct benefits for me or my family as a result of my participation in this research study. I understand that I am free to ask now, or in the future, any questions/concerns I may have about the study or the research procedures. Moreover, I have been assured that records relating to me/my family will be kept confidential, and that no information will be released or printed that would disclose personal identity without my permission.

With respect to both the initial interview and the subsequent private interview, I reserve the right to withdraw from the study at any time and without penalty. I further understand that if I do not participate in this study, or if I withdraw from it at any time and for whatever reason, that the quality of rehabilitative care my family receives will not be compromised in any way.

I hereby consent to participate.

_________________________________________  __________________________________________
Name (Print)                                            Date

_________________________________________
Signature of Participant

_________________________________________
Signature of Witness

_________________________________________
Signature of Researcher

I am additionally aware that a tape recorder will be used during the second interview session, and that the recorded tape will be destroyed once the project is completed. I authorize the researcher to tape record the private interview, as indicated below.

Authorization to utilize tape-recorder:  Yes ______    No ______
Appendix D

Standardized Approach for Participant Recruitment

Hi [client name],

How are you? [rapport-building]

A colleague of mine, who's a graduate student at Brock University, is conducting a rehabilitation study on families of the brain-injured. Her name is Annik Moyal-Waldman. Annik is interested in speaking with you about your perceptions on the quality of family service you received. She'd like to learn about your family's needs, and whether you have any recommendations as to how to improve upon the quality of service to families of the brain-injured.

I was wondering if I could obtain your permission for Annik to contact you to discuss the study?

Your agreement does not mean that you have agreed to participate in it. It only means that you are interested in discussing the study with her.

Thank you! Annik will be contacting you within the next couple of days.

[Closure]
Appendix E

Initial Client Contact Form
(Culled from Client File Reviews)

Full Name of Primary Caregiver/Age: 

Tel # (Home): 

(Work): 

Name of injured person: 

Name of other family members & respective ages: 

Date of MVA: 

Diagnosis: 

Level of severity: 
(Mild, moderate, or severe? Must be "severe" traumatic brain injury to meet inclusion criteria)

Nature of injury: 
(To meet inclusion criteria, the injured individual has sustained a traumatic brain injury, not an acquired brain injury. Furthermore, he/she has sustained a closed, not an open, injury)

Level of social displacement: 
(i.e., community integration - mild, moderate, or severe degree of social displacement? Again, must be a significant/severe degree of social displacement to qualify)

Discharge date from Riverdale Hospital: 

Time elapsed since discharge (must be at the very least 6 months past rehab hospital discharge date, and ideally beyond 1 year past discharge date): 

Injured individual living at home? 
(it is preferable, but not necessary, that the injured individual be residing with primary caregivers)
What kinds of services have you used since injury? (Test degree of insight and experience with family service)

This is to authorize Annik Moyal-Waldman to contact the above-mentioned client for the purpose of describing the research study in further detail, and determining the degree of interest in participating in the research.

[Contact's Name] [Name of organization] 

Date

Please return to ANNİK MOYAL-WALDMAN via [fax number]
Appendix F

Pilot-testing Information Package

Ms. Annik Moyal-Waldman

[Address]

May 1, 1995

VIA FAX

[Addressees]

Dear Rehabilitation Practitioners,

Further to our initial discussion in September '95, in which you kindly assisted me in formulating ideas for my thesis research, I am pleased to submit to you an outline of my research proposal, in partial fulfillment of my Master of Education degree requirements. I would like to take this opportunity to thank you all personally for your contributions to my thesis research, and am pleased to advise that my research proposal has now been approved and accepted by both the thesis committee and the Standing Subcommittee on Research with Human Participants of Brock University, St. Catharines, Ontario.

With this in mind, I would now like to request your assistance with the pilot-testing of my instruments. Enclosed please find copy of pilot guidelines, and copies of both instruments (i.e., Family Participant Questionnaire and Family Interview Guide).

I would greatly appreciate receiving your feedback at your earliest convenience, as I plan to begin data collection in mid-May/early June. My home address is indicated above; alternatively, I'd be interested in reviewing your comments via fax. My fax number is [fax number]. In the meantime, I would like to extend to you my warmest wishes for a wonderful Spring/Summer, and look forward to sharing my results with you upon completion. If you have any questions or concerns, please feel free to contact me at my home office at [telephone number]. I look forward to receiving your feedback, and thank you in advance for your much-appreciated assistance!

Warmest Wishes,

Annik

Encls. Family Pre-Consent Form
Pilot-testing the Family Participant Questionnaire
Pilot-testing the Family Interview Guide
Family Participant Questionnaire
Family Interview Guide

.../...
**Family Pre-Consent Form**

**Title of Research Project:**  
*Families of the traumatically brain-injured: A Case Study Approach to Perceptions of Quality of Service, Degree of Satisfaction, and Family Needs*

**Researcher:**  
Ms. Annik Moyal-Waldman, B.A. (Hons.), Psychology/Philosophy  
M.Ed. Graduate Student  
TEL: (416) 493-7583

**Academic Supervisor:**  
Dr. R. Terrance Boak, B.Sc, B.Ed, M.Ed., P.hD.  
Dean of the Faculty of Education, Graduate Studies  
TEL: 1 (905) 688-0550, ext.3710

**Background and Purpose of Research:**

Hi! My name is Annik Moyal-Waldman. I am a graduate student in the Faculty of Education at Brock University. In partial fulfilment of my degree requirements, I am conducting a research study under the supervision of Dr. Terrance Boak. I am interested in learning about families of brain-injured individuals. The intent of this study is to foster an understanding of the rehabilitation counselling practice of families of the brain-injured. Its purpose is twofold. Firstly, I would like to learn about your perceptions, concerning the degree of satisfaction with the quality of family service you received. In addition to fostering an understanding of current satisfaction levels, my second aim is to obtain your recommendations for a future program based on related and current family needs.

**Procedure:**

If you agree to participate in this study, I will first meet with you and your relative to personally assure you of anonymity and confidentiality. At this time, I will briefly reiterate the nature of the research, its purpose, and procedures, as well as respond to any questions or concerns you may have. In the same meeting, I will request that you complete a brief questionnaire, administered by myself. The questionnaire should take no longer than 10-15 minutes. In the questionnaire, I will ask you to tell me about who you are, and a bit about your family also.

In the second private interview, we will meet at a time and location chosen by you, for approximately 1 hour. I will meet with your relative privately at another time. At this session, I will ask you about your feelings regarding the quality of family services received, as well as your satisfaction with such service, and whether or not there were any gaps in the delivery of service. I will then ask you about your family’s needs, and the means by which these might be incorporated into a future program for families of the brain-injured.

Lastly, I will provide you with a typed copy of the transcript of your previous interview, and ask you for any input/comments/feedback. It is my opportunity to check that I have correctly heard and understood everything that you have said. It is also your opportunity to re-read the transcript, to correct or change anything you have stated. If there are any changes at all, I will happily update your transcript accordingly.

**Benefits:**

Information gained from the study will help rehabilitation practitioners better understand the needs of families of the brain-injured. It may therefore also improve the overall quality of health care to families of the brain-injured.
The text on the page is not legible and cannot be accurately transcribed.
Confidentiality:

I want to assure you of utmost confidentiality and anonymity. All information that is gathered, be it through questionnaire or private interview, will be utilized for the sole & exclusive purpose of this research study. With your permission, I will tape-record the interview to be sure I can recall all that you tell me. Recorded tapes will be destroyed upon completion of this study.

Because your participation in this study is entirely voluntary, you will have the option, at any time, to withdraw without any penalty. I would like to invite you to contact me at (416) 493-7583 should you have any questions or concerns, now, or in the future. Alternatively, you may contact Dr. Terrance Boak, Dean of the Faculty of Education, Academic Supervisor, at Brock University, St. Catharines, 1 (905) 688-0550, ext. 3710. We will be happy to discuss them with you, and thank you for your time and consideration.

Sincerely,

Annik Moyal-Waldman
Annik Moyal-Waldman, M.Ed. Graduate Student
Pilot-testing the Family Participant Questionnaire

In order to assist me in determining that I have appropriate and useful questions for my study, I would appreciate your constructive comments regarding the *Family Participant Questionnaire*. Thanks for your valuable input!

1. Adequate and relevant background information:

2. Clarity of questions:

3. Grammar usage:

4. Ease of comprehension; reasonable level of difficulty of questions:

5. Approximate time required to respond to questions:

6. Overall organization and presentation of the document:

7. Additional Comments:

Signature: ____________________________________________
Pilot-testing the Family Interview Guide

In order to assist me in determining that I have appropriate and useful questions for my study, I would appreciate your constructive comments regarding the *Family Interview Guide*. Thanks for your valuable input!

1. Adequate and relevant background information:

2. Clarity of questions:

3. Grammar usage:

4. Ease of comprehension; reasonable level of difficulty of questions:

5. Approximate time required to respond to questions:

6. Overall organization and presentation of the document:

7. Additional Comments:

Signature:  ____________________________________________
# CIQ

**Community Integration Questionnaire**

Revised 1995

<table>
<thead>
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<th>Field</th>
<th>Information</th>
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<tr>
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</tr>
<tr>
<td>ID Number</td>
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</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
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<tr>
<td>Date of Birth</td>
<td></td>
</tr>
<tr>
<td>Date of Test</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Did a proxy complete the questionnaire?</td>
<td>Yes: [ ]  No: [ ]</td>
</tr>
<tr>
<td>Relationship of proxy to respondent:</td>
<td></td>
</tr>
</tbody>
</table>

**CIQ Score:**
- **Home Integration Scale:**
- **Social Integration Scale:**
- **Productivity Scale:**
- **CIQ Total Score:**

---

**Direct Correspondence to:**

Ontario Brain Injury Association  
Centre for Training and Education  
P.O. Box 2338  
St. Catharines, ON  
L2M 7M7  
Ph: (905) 641-8877  
Fax: (905) 641-0323

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Community Integration Questionnaire

1. Who usually does shopping for groceries or other necessities in your household?
   - yourself alone
   - yourself and someone else
   - someone else

2. Who usually prepares meals in your household?
   - yourself alone
   - yourself and someone else
   - someone else

3. In your home, who usually does normal everyday housework?
   - yourself alone
   - yourself and someone else
   - someone else

4. Who usually cares for the children in your home?
   - yourself alone
   - yourself and someone else
   - someone else
   - not applicable/ no children under 17 in the home.

5. Who usually plans social arrangements such as get-togethers with family and friends?
   - yourself alone
   - yourself and someone else
   - someone else
6. Who usually looks after your personal finances, such as banking or paying bills?
   - yourself alone
   - yourself and someone else
   - someone else

Can you tell me approximately how many times a month you now usually participate in the following activities outside your home?

7. Shopping
   - Never
   - 1-4 times
   - 5 or more

8. Leisure activities such as movies, sports, restaurants, etc.
   - Never
   - 1-4 times
   - 5 or more

9. Visiting friends or relatives
   - Never
   - 1-4 times
   - 5 or more

10. When you participate in leisure activities, do you usually do this alone or with others?
    - mostly alone
    - mostly with friends who have head injuries
    - mostly with family members
    - mostly with friends who do not have head injuries
    - with a combination of family and friends

11. Do you have a best friend with whom you confide?
    - yes
    - no
12. How often do you travel outside the home?
   - [ ] almost every day
   - [ ] almost every week
   - [ ] seldom/never (less than once per week)

13. Please choose the answer below that best corresponds to your current (during the past month) work situation:
   - [ ] full-time (more than 20 hours per week)
   - [ ] part-time (less than or equal to 20 hours per week)
   - [ ] not working, but actively looking for work
   - [ ] not working, not looking for work
   - [ ] not applicable, retired due to age

14. Please choose the answer below that best corresponds to your current (during the past month) school or training program situation:
   - [ ] full-time
   - [ ] part-time
   - [ ] not attending school or training program

15. In the past month, how often did you engage in volunteer activities?
   - [ ] never
   - [ ] 1-4 times
   - [ ] 5 or more
Background and Rationale

The Community Integration Questionnaire (CIQ) is intended as a brief, reliable measure of an individual's level of integration into the home and community. The CIQ was developed by a small group of experts interested in assessing community integration for persons who have experienced traumatic brain injury. These experts met together to establish a consensus on what characterizes an individual's experience in the community, especially after the acute rehabilitation phase.

It is important to note that this questionnaire represents a finite set of indicators of community integration, and as such does not encompass all possible indicators of integration. Therefore, it is recommended that the CIQ be used in concert with similar assessments of impairment, disability, environmental barriers, and demographic descriptors.

Although the CIQ was designed specifically for individuals with traumatic brain injury, it is applicable to all individuals, disabled or not, living outside institutions.

Administration

The CIQ is normally completed by the individual being assessed. In most cases an interviewer should be present to assist with interpretation of specific items. In certain instances, the individual being assessed may not be able to complete the questionnaire (e.g., due to expressive or receptive language deficits, memory impairment, physical disabilities, etc.). In these instances, a person who is familiar with the individual being assessed may complete the form, provided that the individual being assessed is present when the form is completed.

Most of the questions are directed at how the individual performs a specific activity within the household or the community. Responses usually indicate that the individual performs the activity alone, with another person, or that the activity is typically performed by someone else. For some responses, the individual being assessed may find it difficult to decide which response fits best with how a particular activity is performed. In these instances, the individual should be encouraged by the examiner to choose the response reflecting the usual or typical performance of that activity.
Community Nutrition Cautions

and Snacks, etc.

Analysis of Pediatric Nutrition

Introduction

The purpose of this chapter is to examine the importance of pediatric nutrition. Pediatric nutrition is a critical aspect of child development and well-being. It involves the provision of appropriate nutrients to ensure optimal growth, development, and health. The nutritional needs of children change throughout their development, from infancy through adolescence. Understanding these needs is crucial for promoting healthy growth and development.

Pediatric nutrition is particularly important in the early stages of life, as the rapid growth and development of the first few years of life require adequate nutrition to support organ development, muscle growth, and brain development. Poor nutrition during these critical periods can result in growth retardation, cognitive impairment, immune system weakness, and increased risk of chronic diseases later in life.

In this chapter, we will explore the nutritional needs of infants and children, including the importance of breastfeeding, the transition to solid foods, and the role of micronutrients. We will also discuss the impact of malnutrition on child health and the strategies for promoting healthy growth and development.

Chapter Outline

I. Introduction
   A. Purpose of the Chapter
   B. Importance of Pediatric Nutrition
II. Nutritional Needs of Infants
   A. Breastfeeding
   B. Solid Foods
III. Nutritional Needs of Children
   A. Micronutrients
   B. Energy Balance
IV. Malnutrition and its Impacts
   A. Undernutrition
   B. Overnutrition
V. Promoting Healthy Growth and Development
   A. Strategies for Healthy Eating
   B. Monitoring Growth and Development

References

This chapter is based on several references, including a recent study on the importance of breastfeeding, a review of the role of solid foods in child development, and a comprehensive guide on pediatric nutrition. The sources cited in this chapter provide a solid foundation for understanding the nutritional needs of infants and children and the strategies for promoting healthy growth and development.
Scoring Guidelines

The CIQ consists of a total of 15 questions. The overall score, which represents a summation of the scores from individual questions, can range from 0 to 29. A higher score indicates greater integration, and a lower score reflects less integration. The CIQ can be further divided into three subscores, corresponding to integration in the home, social integration, and productivity. Procedures for deriving the subscores are outlined on the scoring sheet.

The following guidelines provide scoring information for specific items or groups of items.

Items 1 to 6:

Score:
2 = The activity is performed alone
1 = The activity is performed with someone else
0 = The activity is performed by someone else

Note: For item 4, if there are no children under 17 in the home, the average (mean) score for items 1 through 3 and item 5 should be substituted.

Items 7 to 9:

Score:
2 = The activity was performed 5 or more times in the past month
1 = The activity was performed 1 - 4 times in the past month
0 = The activity was not performed in the past month

Item 10

Score:
2 = Mostly with friends without head injury or combination of family and friends
1 = Mostly with friends who have head injuries or with family
0 = Mostly alone
Item 11
Score:
2 = Yes response
0 = No response

Item 12
Score:
2 = Almost every day
1 = Almost every week
0 = Seldom/never (less than once per week)

Items 13 to 15
Although these items are collected individually, they will be combined to form one variable, Productivity. The scoring of this variable is dependent on the combination of answers to questions 13, 14 and 15. On page 4, is a listing of answer sets to these questions and their associated score.
### Scoring of the Productivity Variable

<table>
<thead>
<tr>
<th>Question#13</th>
<th>Question #14</th>
<th>Question#15</th>
<th>Score</th>
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<tbody>
<tr>
<td>Work</td>
<td>School</td>
<td>Volunteer Work</td>
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<tr>
<td>Not working/not looking</td>
<td>No school</td>
<td>No Volunteering</td>
<td>0</td>
</tr>
<tr>
<td>Not working/not looking</td>
<td>No school</td>
<td>1-4 times/month</td>
<td>1</td>
</tr>
<tr>
<td>Not working/not looking</td>
<td>No school</td>
<td>5 or more times/month</td>
<td>1</td>
</tr>
<tr>
<td>Not working/looking</td>
<td>No school</td>
<td>No Volunteering</td>
<td>0</td>
</tr>
<tr>
<td>Not working/looking</td>
<td>No school</td>
<td>1-4 times/month</td>
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</tr>
<tr>
<td>Not working/looking</td>
<td>No school</td>
<td>5 or more times/month</td>
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<tr>
<td>Retired due to age</td>
<td>No school</td>
<td>No Volunteering</td>
<td>0</td>
</tr>
<tr>
<td>Retired due to age</td>
<td>No school</td>
<td>1-4 times/month</td>
<td>2</td>
</tr>
<tr>
<td>Retired due to age</td>
<td>No school</td>
<td>5 or more times/month</td>
<td>3</td>
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<td>4</td>
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<tr>
<td>Retired due to age</td>
<td>Part-time</td>
<td>1-4 times/month</td>
<td>5</td>
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<tr>
<td>Retired due to age</td>
<td>Part-time</td>
<td>5 or more times/month</td>
<td>5</td>
</tr>
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<td>Retired due to age</td>
<td>Full-time</td>
<td>Any answer</td>
<td>5</td>
</tr>
<tr>
<td>Not working</td>
<td>Part-time</td>
<td>Any answer</td>
<td>3</td>
</tr>
<tr>
<td>Not working</td>
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<td>Any answer</td>
<td>4</td>
</tr>
<tr>
<td>Part-time</td>
<td>No school</td>
<td>Any answer</td>
<td>3</td>
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<tr>
<td>Part-time</td>
<td>Part-time</td>
<td>Any answer</td>
<td>4</td>
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<tr>
<td>Part-time</td>
<td>Full-time</td>
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<td>5</td>
</tr>
<tr>
<td>Full time</td>
<td>No school</td>
<td>Any answer</td>
<td>4</td>
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<td>5</td>
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<tr>
<td>------------</td>
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<td></td>
</tr>
<tr>
<td>1</td>
<td>Shopping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Prepare Meals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Housework</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Caring for Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Social Arrangements</td>
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<td>HOME INTEGRATION SUBSCALE</td>
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<tr>
<td>6</td>
<td>Personal Finances</td>
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<td>7</td>
<td>Shopping (times/month)</td>
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</tr>
<tr>
<td>8</td>
<td>Leisure activities (times/month)</td>
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<td></td>
</tr>
<tr>
<td>9</td>
<td>Visiting friends or relatives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Leisure activities (with whom)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Having a best friend</td>
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<td></td>
<td>SOCIAL INTEGRATION SUBSCALE</td>
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<tr>
<td>12</td>
<td>Travel outside of home</td>
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<td>13, 14, 15</td>
<td>Productivity</td>
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<td></td>
<td>CIQ TOTAL SCORE</td>
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L2M 7M7  
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Fax: (905) 641-0323  

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Subscales

Subscales have been developed to allow an analysis of integration within specific domains of everyday life. Items have been grouped with respect to their association with: 1) activities primarily related to the home; 2) activities associated with socialization; and 3) educational or vocational activities. These groupings have been made both logically and on the basis of principal components analysis of items which cluster together. Separate home integration, social integration and productivity subscale scores are derived as follows:

Home Integration: Summation of items 1 through 5
Social Integration: Summation of items 6 through 11
Productivity: Summation of item 12 and the Productivity variable

The overall CIQ score is the additive sum of items 1 through 12 and the Productivity variable.
Appendix H

Family Participant Questionnaire

Thank you for your interest and participation in this research study! As you know, I am currently conducting research for my Master of Education thesis in partial fulfillment of program requirements. I am very excited about the possibility of learning about your perceptions concerning the degree of satisfaction with the quality of family service you received. In addition to fostering an understanding of current satisfaction levels, I am interested in obtaining your recommendations for a future program based on related and current family needs. Your comments can help make a difference for other families who live with the effects of brain injury!

This questionnaire constitutes my first opportunity to get to know you a little bit. The attached is a series of questions that tells me about who you are and informs me about your family, family membership, structure, the nature of your loved one's injury, etc. Please rest assured that all information, relating to you/your family will be kept strictly confidential, by myself, the researcher. No information will be released or printed that would disclose personal identity without permission.

I would greatly appreciate your efforts in answering all questions as legibly as possible, and to the very best of your ability. Thank you!

Annik Moyal-Waldman

* All sections designated by (*) have been reproduced from "Caregiver Information Support Link (CISL)." The CISL contains questionnaires copyrighted by Dr. Barry S. Willer (1991), and are used with the permission of the author. Permission for use was obtained from Dr. Barry Willer, Research Director, The Ontario Brain Injury Association, regarding the reproduction of this specific material.
Family Participant Questionnaire

I. PERSONAL HISTORY

PARTICIPANT'S NAME (PRINT): ________________________________

ADDRESS: ______________________________________________________

WORK TELEPHONE: ( ) ____________________________

HOME TELEPHONE: ( ) ____________________________

The most suitable days/times to connect with you are: ________________________________

DATE OF BIRTH: ___/___/___
Mth  Day  Yr

SEX: _____ Female  _____ Male

AGE: ______

MARITAL STATUS: Single  _____
Married  _____
Separated  _____
Divorced  _____
Widowed  _____

GROSS ANNUAL FAMILY INCOME: 0-$10,000  _____
$10,000 - $30,000  _____
$31,000 - $50,000  _____
$51,000 - $70,000  _____
$71,000 - $90,000  _____
$91,000+  _____
WORK LIFE:

Are you presently:

- Employed
- Unemployed
- Student
- Part-Time employed
- Full-time homemaker
- Retired

OCCUPATION:

What is your occupation/job? _________________________________

EDUCATION:

What is the highest level of education you have completed to date? (Please circle appropriate number).

1. University Graduate degree
2. University Undergraduate degree
3. College
4. High School
5. Other _________________________________

II. FAMILY MEMBERSHIP

Please indicate all members of your immediate family (including yourself), and all of your respective ages (e.g., Mother, Ellen, 42; Father, Sid, 45; Sister, Ashley, 10; Brother, Matt, 14)

1. _________________________________
2. _________________________________
3. _________________________________
4. _________________________________
5. _________________________________
6. _________________________________

In relation to yourself, please tell me who is the brain-injured family member in your family, by referring to the number in the previous question (e.g., #3 - Ashley, Sister, 10)
STYLE ASST.

SKILLS: 

- Technical 
- Communication 
- Leadership 
- Collaboration 
- Problem-solving 


test

This is a test.

PHYSICAL ASST.

The physical assistant is responsible for:

- Assisting with daily tasks
- Providing light housekeeping
- Assisting with medication management

"Your tasks are as follows:"

- 1. "Perform a comprehensive assessment of the patient's needs."
- 2. "Organize the patient's daily medications and ensure they are taken on time."
- 3. "Collaborate with the healthcare team to ensure the patient's comfort and well-being."
Referring once again to the bottom of p. 2 of this questionnaire, who is/are the primary caregiver(s) for your brain-injured family member?

III. FAMILY RELATIONSHIPS/PRE- & POST-INJURY STATUS:

How would you qualify your family relationships, prior to the traumatic event? (Please circle the appropriate answer).

1. Very close
2. Somewhat close
3. Not close
4. Distant
5. Indifferent

How did your family relationships change, as a result of brain trauma? (Please circle the appropriate answer).

1. My relationships with my family became more distant than before the trauma
2. Even closer
3. Less close
4. No change

IV. *PRESENT LIVING ARRANGEMENTS OF BRAIN-INJURED FAMILY MEMBER (Please circle appropriate number).

1. With your family
2. Family care/foster care
3. Acute care hospital
4. Inpatient rehabilitation hospital
5. Transitional living centre
6. Coma treatment centre
7. Nursing facility
8. Inpatient psychiatric centre
9. Developmental centre
10. Intermediate care facility
11. Supervised community residence
12. Supportive community residence
13. Board & care/Single room occupancy
14. Independent & alone
15 Other (Please specify): __________________________________________

V. DETAILS OF INJURY

DATE OF FAMILY MEMBER'S INJURY: ___/___/___
Mth Day Yr

*INJURY TYPE: (Please circle appropriate number).

1 Driver of an auto in a motor vehicle accident
2 Passenger of an auto in a motor vehicle accident
3 Motorcycle
4 Pedestrian struck by auto
5 Bicyclist struck by auto
6 Bicycle fall
7 Victim of assault
8 Fall
9 Work-related accident
10 Other (please specify) __________________________________________

VI. *FAMILY SERVICE TYPE, USE, & NEED

What types of services have you or your family utilized to help you to cope with the traumatic brain injury of a loved one? Kindly circle all of the appropriate answers and indicate the location where you received such service in the space provided below. Most importantly, please specify whether you/your family actively sought the service(s), [as designated by AS], or had the service(s) offered to you by the service provider [as designated by NAS].

1 Individual counselling __________________________________________

________________________________________

2 Family counselling __________________________________________

________________________________________

3 Family support groups (Local/regional associations) _________________________

________________________________________
4 Education (i.e., via hospitals, rehabilitation centres, other?) ________________________________

5 Education through membership (i.e., Brain injury support organizations. If other, please specify:)

6 Education through other means? (Please specify) ________________________________

7 Other (Please specify) ________________________________

Thank you again very much for your time and participation!
Appendix I

Fieldnotes Guidelines: Observations & Reflections

Title of Research Study: Families of the Brain-injured: A Case Study Approach to Perceptions of Quality of Service, Degree of Satisfaction, and Family Needs

Name of Participant:

Date/time of Meeting:

Data Collection Stage: Orientation
                      Private Interview
                      Transcription

I. THE INFORMANT - Objective-oriented recording:

PARTICIPANT PROFILE: (Setting/atmosphere, portraits of people (i.e., physical appearance, dress, mannerisms, or styles of talking), reconstruction of dialogue/interactions, and actions/ description of events)

HISTORY:
II. THE RESEARCHER - Subjective-oriented recording

This is a license for my "non-neutrality" to emerge. Purpose: insight into myself, as researcher, self-awareness, and self-knowledge. If I am conscious of how I may have been affecting and affected by the data -- then I can improve my data collection processes (Field & Morse, 1985). This is where I document behaviours that affect the observation/human factors (i.e., biases, fatigue, distraction, intuitive thoughts, and emotional reactions)

MY HUMANNESS/BIASES:

INSIGHTS/SELF-AWARENESS:

WHAT MOST IMPRESSED ME ABOUT WHAT I DID:
WHAT I HEARD:

WHAT I SAW:

WHAT I EXPERIENCED:
MY REFLECTIONS:

[Content of the reflection goes here]
Appendix J

Family Interview Guide

Hi, how are you?

Thank you for your agreement to participate in this study. Before we get started, I want to ask you to relax. I want to explain to you what we are about to do to ensure you are clear and comfortable prior to proceeding. I will ask you (3) questions. You will be surprised how quickly answers will come to you! Remember there are no rights or wrongs in the realm of feelings and personal experience.

Try to respond with as much detail and in as much depth as possible. We can take all of our time. I want you to know that I will hear your story without imposing any thoughts, feelings, or judgements upon you. I will listen carefully to what you have to say, with minimal interruption. After you have recounted your personal experience, I will ask you more specific questions about the quality of service you received as a family member. Then, I will thank you, and we will part ways until our "reality check."

Before we begin, I would like to ask you to make one clear distinction in your mind. Any idea what the difference is between direct and indirect services to the families of the brain-injured? Direct services are those that help the family directly in coping or adjusting to the brain injury of a loved one (e.g., education, counseling, support, respite, etc.). Indirect services are those that assist the brain-injured family member in his/her recovery or adaptation to disability (e.g., nursing and medical care, physiotherapy, occupational therapy, speech therapy, neurosurgical, neuro-psychological, or psychological treatment, chiropractics, massage therapy, etc.). These are said to be indirect because they affect you, as a family member only indirectly, since evidently they help your injured family member get better. Do you see the difference? Good. What I am interested in this research are the direct services exclusively, (i.e., the service YOU received directly, as a family member.)

Do you have any questions? OK, are we ready?

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From the moment you first heard the news of your family members' trauma, you entered a whole new world. Suddenly, your family member was thrust into a gamut of services you probably never even heard of before, let alone experienced. By virtue of your status as a family member, you were introduced to, and entitled to, a number of different services to help you to deal with the experience, and to help you adjust and cope with your family members' traumatic brain injury.

You indicated on your questionnaire that the services you(r) family have utilized include:

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

.../...
What I would like to ask you to do now is, describe in your own words, what you feel about the quality of family services you received, as a family member, following the brain injury of your family member. How satisfied are you with the family service you have received? What, if any, gaps are there in the delivery of service?

What are your family's present needs, if any, as a result of the traumatic brain injury of your family member?

What are your recommendations as to how to improve the quality of service to families of the brain-injured? How might rehabilitation practitioners incorporate these into a future program for families of the brain-injured?

Specific questions concerning experience with particular aspects of service:

What are your feelings concerning the quality of service you received at various stages of your adjustment: (i) immediately upon onset of trauma; (ii) when your injured family member underwent rehabilitation, and (iii) when he/she entered the community or home again?

What did rehabilitation practitioners do that you found helpful/unhelpful in coping?

What is important to you when you receive education, counselling, or support services as a family member?

What components of service did you find most/least helpful?

How satisfied were you by the way in which rehabilitation practitioners communicated with you? Did you feel heard and listened to?

How available were these professionals to assist you?

How accessible were the services? How did you find out about the services utilized?

Thank you once again, ____________________________, for your participation!