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**FAMILY MEMBERS' EXPERIENCES OF LIVING WITH
A TRAUMATICALLY HEAD-INJURED PERSON:
AN EMPIRICAL-PHENOMENOLOGICAL STUDY**

**Elaine Leslie Clark
May, 1995.**

**A Thesis Submitted to the School of Graduate Studies of the
University of Ottawa as Partial Fulfillment of the Requirements
for the Degree of Doctor of Philosophy**

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DEDICATION

Families provide us with our beginning and they provide us with our first social world. Whether present or absent, families provide us with the groundwork from which our lives emerge and develop. My own experience of living with a head-injured daughter led me to wonder how such an event affected the lives of other families. And so the family became the foundation for this doctoral dissertation project.

Therefore I dedicate this thesis to my family. In particular, I dedicate my work to my late father, Joseph Kohut, who gave me the love of learning and to my mother Antoinette Klochan Kohut, who gave me perseverance; to my children Natasha, who offered her encouragement and support from a distance, to Frederick, who engaged in helpful discussions and inquiries and to Triana, who offered encouragement and personal inspiration; and finally, to my husband James Lee Clark, Jr. for sharing the stresses inherent with the dissertation process and for his unending support and encouragement through the long hours and months of my labour.

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Phenomenological research demands reflection and perseverance. At times it is a long and arduous journey. Yet in the end, it provides a rich and rewarding experience. Throughout the years of this doctoral project there have been many who have provided knowledge, encouragement and counsel. To all of you I extend my sincerest appreciation and gratitude.

I would like to first thank Bertha Mook, Ph.D., my dissertation supervisor, for her invaluable advise, direction and phenomenological inspiration, especially during the final months as we raced the clock to meet our submission deadline. To committee members Michel St. Germain, Ph.D. and Augustine Meier, Ph.D., I extend my appreciation for their thought provoking questions and suggestions and especially for their encouragement and enthusiasm for my project. To Amedeo Giorgi, Ph.D., committee member at a distance, I extend a thank you for invaluable methodological suggestions and to Robert Flynn, Ph.D., a sincere thank you for last minute comments and suggestions.

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To the School of Psychology at the University of Ottawa I gratefully acknowledge their financial support especially during the final semesters, which enabled me to devote all my energy to completing the dissertation.

To friends, colleagues and family members who provided extra encouragement and often a listening ear, and to my daughter Triana who

struggles valiantly to overcome her own head injury, I extend a heartfelt thank you.

Finally, I extend my sincerest appreciation to the two head-injured young adults and their families who generously shared their experiences with me. You have given meaning and significance to this doctoral project.

ABSTRACT

Significant improvements in medical and neurosurgical interventions have resulted in a substantial increase in the number of persons surviving traumatic head injury. Consequently, more survivors and their families find themselves having to learn to cope and live with the impairments that accompany head injury. While the nature and degree of recovery is often difficult to pre-determine, most individuals require a comprehensive spectrum of medical, rehabilitative and supportive services to facilitate and maintain the recovery process.

The complex nature of family life involving shared living-space, time and history, and the multiplicity of sequelae which impact on family life following traumatic head injury, challenge traditional research methods. In response, recent research studies, which centre on the alterations to family life following head injury, have endeavoured to include qualitative dimensions along with quantitative measures in order to provide a more comprehensive picture of the difficulties faced by families. These studies also fall short of investigating the deeper dimensions of family life, namely the intersubjective realm.

Using an existential-phenomenological research approach, we have undertaken an indepth investigation of one family whose young adult son sustained a traumatic head injury resulting in severe impairment including loss of communication and movement. Applying an adapted version of Giorgi's systematized phenomenological method, our investigation revealed a temporal unfolding of three phases through which the family moved in its experience of living with a traumatically head-injured person: a pre-accident life-world, a phase of living with the immediate experience of the accident and a readjusting phase where family members worked to recreate and regain a sense of familial wholeness. As well, the disruption and disconnection experienced by family

members following the accident was shown to originate from a deeper disruption at the foundational level of human existence.

The structural matrix of themes that constituted our research family's life-world following this tragic accident was dominated by the themes of brokenness and disconnection, a restricted life-world, a disparity between inner and outer family life and a call to care. The Heideggerian theme of care was the family's existential response to the "broken" existence and near loss of their family member. It emerged as the underlying theme which held together and guided the reconfigured familial structure.

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Chapter I

INTRODUCTION

It is only now, years later that I can begin to assess the impact. I must stress again that head injury to one family member damages all family members, and recovery involves the recovery of all family members. It is indeed a shared journey, every step of the way. (Linge, 1988, p.3)

Every year it is estimated that 50,000 Canadians sustain traumatic brain injuries. Though physically many victims appear unchanged, their lives and the lives of their families will probably never be the same (Colcleugh, 1991, p. 38). Significant improvements in medical and neurosurgical interventions have substantially increased the number of people surviving head injury. This means that many more patients and their families have to learn how to cope and to live with the impairments which frequently accompany brain injury. While the nature and degree of recovery of function are often difficult or impossible to predetermine, most injured individuals require a comprehensive spectrum of medical, rehabilitative and supportive services to help them recover and maintain this recovery.

Historically, Canada's health care system has provided medical and basic rehabilitation needs. Unfortunately, recent advancements in head injury rehabilitation have not been fully integrated into our universal health care system, largely due to lack of funding. Thus, many families are left to manage as best they can with their convalescing family member.

At present, a substantial body of research literature, both theoretical and applied, pertaining to traumatic head injury exists and is in progress. Mainstream medical research has traditionally focused on the epidemiology of the phenomenon and on survival and groups at risk. As well, there is a growing body of literature on practical interventions and services. Research on the

family has mostly centred on family functioning, i.e. how families respond to and cope with trauma and chronic illness or disability due to traumatic head injury.

In recent years, descriptive research into the difficulties experienced by families who care for a head-injured family member has started to appear. While recognizing the impact of such an injury on the entire family, this research has centred on the experiences of the primary caregiver, often the mother, spouse or in some cases a special needs attendant, or on the joint experiences of the head-injured person and a significant other. But family life is unique in that it is truly interrelational and interactive, involving shared living-space, history, aspirations and dreams of the future. Consequently, the phenomenon of a head injury does not occur in an interpersonal vacuum. According to Miller (1993), from the first critical stages of the injury to whatever ultimate long-term resolutions are reached, the patient's significant others play a crucial role in determining the kind of post-injury life the person will have. We also know that the patient's response to his or her injury will have a profound impact on the family dynamics after he or she returns home and things supposedly "settle down".

To address the complexity and far-reaching nature of the phenomenon of traumatic head injury, we have undertaken an empirical-phenomenological study: Family Members' Experiences of Living with a Traumatically Head-Injured Person. Our aim was to extend and enrich the explication and understanding of the experience of living with a head-injured person within a family context. An empirical-phenomenological method was used to access the uniquely human dimension of family life and the living-together over time as an intimate social group. The phenomenological method used derives from the Duquesne method systematized by Giorgi (1985), and adapted to the study of

the family by Mook (1985, 1986a, 1987) and Emmrys (1993) at the University of Ottawa.

Situated within a human science research approach, existential-phenomenological research studies the phenomena of human living, and is thus intrinsically different from a natural science approach. An unequivocal respect for the complexity of human existence is central to this approach. It seeks to gain a deeper understanding of the nature or meaning of our everyday experiences. More specifically, it is a systematic attempt to uncover and describe the inherent meaning structures of the phenomena of lived experience.

In this dissertation study, we intend to reveal, through a phenomenological analysis of written descriptions and in-depth family interviews, the changes to the structural configuration of family life which emerge in response to the occurrence of a traumatic head injury in one family member. As well, a phenomenological portrait of family members' embedded experiences, perceptions and feelings of self and other family members will be presented, along with their perceptions and expectations of the present and the future in light of this experience.

The dissertation includes the philosophical foundations of a human science research approach, an overview of the literature pertaining to traumatic head injury and its impact on families, the phenomenological methodology used for the study, results of the research analysis, and a discussion of the research findings. More specifically, the philosophical foundations chapter includes the primary contributors to the human science research approach, foundational concepts for an existential-phenomenological approach and a rationale for using an empirical-phenomenological method in this study. The literature review chapter presents mainstream studies of head injury and

families dealing with a head-injured person, as well as the existential-phenomenological literature on tragedy, traumatic head injury and research into family life. The transitional position of Kurt Goldstein will also be addressed in the literature review chapter. The methodology chapter includes a discussion of the phenomenological research method, the basic characteristics of empirical-phenomenological research, and the proposed research method for this study. The results chapter presents the situated structures of individual family members' written protocols and the situated structure of the family interviews. Finally, the discussion chapter describes the underlying themes within the situated structures and the Heideggerian notion of care as an existential response to traumatic head injury, followed by a dialogue with previous research studies, clinical implications, limitations of the research and implications for future research.

Chapter II

PHILOSOPHICAL FOUNDATIONS OF A HUMAN SCIENTIFIC APPROACH

The decision to use a research method grounded in the human sciences originates from recognizing the need for a different paradigmatic approach to studying traumatic head injury and its impact on family members. Most importantly, a human science research approach and in particular, an existential-phenomenological one, is able to access and respond to those aspects of human life that cannot be easily operationalized or measured by traditional natural science methods. Furthermore, it recognizes that the social world is integrally interwoven and therefore inseparable from the individual's world, thus warranting inclusion in the research analysis.

A human science research approach holds to certain concepts and ways of thinking. To better understand the foundation on which the present study rests, this chapter will highlight the seminal ideas of the primary contributors and the foundational concepts that underlie human science research in general and an existential-phenomenological approach in particular. It will conclude with a rationale for choosing an empirical-phenomenological research method to the study of traumatic head injury as it pertains to family life.

Primary Contributors to a Human Science Research Approach

Every research approach has its notable scholars and thinkers. For those of us who espouse a human scientific research paradigm, the writings of Dilthey, Husserl, Heidegger and Merleau-Ponty are foundational. Working independently for the most part, Dilthey and the later Husserl contributed to divergent but interrelated foundations of the human science approach. Both proposed distinctly different research methods that were capable of addressing the phenomena of human experience and life. Dilthey called for a qualitatively different paradigmatic approach to the study of human experience. He also

formulated a descriptive research method specifically suited to the study of human experience which he later modified to accommodate the hermeneutic dimension of human experience. Husserl, on the other hand, concentrated on developing a rigorous scientific approach, phenomenology, that primarily focused on disclosing the meaning-structures of human experience. The foundational ideas of Dilthey and Husserl were taken up, refined and integrated by the later existential-phenomenological scholars, Heidegger and Merleau-Ponty. Together, their ideas and concepts form the foundation on which this research study is based.

Dilthey

The writings of Wilhelm Dilthey gave a major impetus to the human science movement. In his Introduction to the Human Sciences (1989/1883), he laid out the basic concepts and preliminary means to investigate human experience as well as the course for a human scientific approach to research. Specifically, Dilthey articulated a rationale for a different paradigmatic approach to the Geisteswissenschaften or human sciences and laid the foundation for a formal human science methodology.

Dilthey's writings initially focused on a critique of psychologists' efforts to gain "scientific" legitimacy by embracing natural science models and methods (Karlsson, 1993). He emphasized that psychology should try to understand the psyche rather than try to explain it within the tradition of the natural sciences. The object of the human sciences should not be to explain but to understand life in terms of life itself. To do this, we must look to the "categories of life" that are rooted in the reality of lived experience.

To legitimate the need for a different paradigmatic stance, Dilthey identified several characteristics he considered to be uniquely indicative of human existence, i.e. the world of the mind, temporality, lived-experience, and

expressions of life. In the broad and vague concept of "world of the mind", Dilthey referred to human intellectual and creative capacities, which include capacities for logical and abstract thinking, for a sense of purposefulness, and for an awareness of the historicity of human life (Rickman, 1979).

Dilthey identified temporality as the pre-eminent category of human life (Dilthey in Mueller-Vollmer, 1985). While his articulation of the unique influence of time on human existence is not necessarily new, what is important is his perception of how the experience of time is integrally interwoven into our everyday existence and how it serves as a co-determinant of the content of our lives. For Dilthey, time is the synthesizing agent of our consciousness. It is experienced as a "restless progression" where the present constantly becomes the past and the future the present. He showed that the present holds a special position in that it "fills each moment of time with reality" (Dilthey in Mueller-Vollmer). Because this "filling with reality" is ongoing and never ending, the content of our experience changes constantly and becomes qualitatively different depending on whether we look from the present back to the past or forward to the future. For example, the past cannot be changed, for it exists already, and the future is endowed with possibilities since it has yet to come into existence. Furthermore, in looking back we are passive, while in looking forward, we are active and free.

Dilthey further postulated that the concept of "lived-experience" is the smallest unit in the "flow of time" (Dilthey in Mueller-Vollmer). It is not simply inner experience; it is rather the synthesis of our mental, cultural and physical realities fused within the temporal flow of life. What is unique to lived-experience is that it eludes observation (Dilthey, 1978). When we fix our attention on our lived-experience by conscious observation, the process is halted and pure experiencing is extinguished. What remains is the invariant

form or structure, the structural interconnections of our lived-experience. Dilthey's concept of lived-experience thus anticipates the later phenomenological investigations of Husserl.

To be able to access the content or nature of lived experience, we must look to the "expressions of life", which Dilthey also termed the "objectifications of experience" (Makkreel, 1977, p. 12) or the "outer manifestations of mental content" (Dilthey in Mueller-Vollmer, p. 153). For Dilthey, expressions of life manifest themselves in a variety of forms and levels of abstraction or classes, from the theoretical (concepts and judgments) to the practical (personal actions) and to the experiential (extensions of our emotions and imagination). They provide the foundational starting points of human science studies which may then be probed for their inner experiential meanings (Makkreel, 1977).

Dilthey's early methodological investigations focused on the development of a descriptive psychology that was both analytical and able to access human experience through "expressions of life". Descriptive analysis was guided by the underlying sense of the totality of the interrelated dimensions of lived-experience. Consequently, the fundamental task of descriptive analysis was to explicitate this sense of the whole, as well as the nexus or interconnectedness between the constituents of the phenomenon under investigation. This was in contrast to a natural science approach that combined elements of the phenomenon under investigation in a basically artificial manner (Makkreel, 1977). As his thinking evolved, Dilthey recognized the relevance of an hermeneutic approach to the study of human experience. This shift in his thinking was, in part, based on his recognition that Verstehen, the German word for understanding, was more suitable to the comprehension of lived human experience because it was more sensitive to the dynamic nature of human phenomena as well as to the interrelational dimension of human reality.

Furthermore, Dilthey realized that all initial psychological claims were in reality subject to re-interpretation and refinement. Thus Verstehen was like an act of creation in that it consisted of a "re-experiencing and a re-construction of the author's experience" (Palmer, 1969, p.123).

The essay, "The Understanding of Other Persons", written around 1910, contains Dilthey's mature thoughts on the hermeneutic approach. Building on the work of Schleiermacher (who reconceived hermeneutics as a "general hermeneutics" with principles suitable to all textual interpretation), Dilthey renewed and advanced the notion of hermeneutics as a core discipline able to serve as the foundation of all the Geisteswissenschaften, or human sciences. He explained the principle of the hermeneutic circle as a process where the whole receives its definition from the parts and reciprocally, the parts can only be understood in reference to the whole. Due to the circular nature of the hermeneutic process, every part presupposes the others and every act of understanding is embedded within a context, a horizon, or frame of reference. Furthermore, Verstehen was now conceived as the means to clarify the inherent interconnections between constituents of the phenomenon in terms of the meaning-relations between them (Makkreel, 1977)

To summarize, Dilthey's contributions to human science research included the identification and description of foundational concepts such as lived-experience, Verstehen, expressions of life, temporality and historicity, as well as the formulation of a descriptive research method specifically suited to exploring the experiences of human life. His later writings illustrated a further refinement in his thinking about the hermeneutic nature of human understanding. To this day, Dilthey remains a pillar of the human science movement for his seminal ideas laid the foundation stones for later scholars.

Husserl

While Dilthey sought to develop a descriptive and later an interpretive method for the study of human phenomena, Edmund Husserl devoted his energies to developing phenomenology as a philosophy and a rigorous scientific research method. Specifically, the sole focus of his phenomenology as a descriptive research method was on the disclosure of the primary givenness of the meaning of phenomena in human consciousness. Although, Husserl's thinking underwent many changes and refinements, his commitment to the ideal of a rigorous science never wavered (Spiegelberg, 1965). Even in his final works, his central interest remained focused on individual subjectivity and conscious intentionality (Carr, 1987).

For Husserl, phenomenology is both a discipline and an attitude of the mind. As a discipline, its purpose is to describe that which is "given" in experience without obscuring preconceptions, theoretical speculations or opinions. As an attitude of the mind, it helps reveal the essential structures of a given phenomenon. According to Husserl, phenomenology offered the only way out of the impasse that philosophy found itself in at the end of the nineteenth century, when the realists who affirmed the independent existence of the object, and the idealists who affirmed the priority of the subject, had settled into a stalemated war (Barrett, 1962). Like Dilthey, Husserl felt that philosophy must turn to pure description instead of making intellectual speculations about reality. To this end he emphasized that description must return "to the things themselves", Zu den Sachen selbst. By taking this position, he became the most influential force upon a whole generation of German philosophers who had matured around the time of the First World War (Barrett, 1962).

Many consider Husserl's new formulation of Brentano's concept of intentionality as one of his most influential contributions to the human sciences.

Husserl defined intentionality as the essence of consciousness that enables us to understand how knowledge is constituted in consciousness. Drawing on the formulation made by Brentano that consciousness was always directed toward something, Husserl demonstrated that the subjective and objective dimensions of consciousness are inseparably interwoven. He identified the objective dimension as noema or the intended object, and the subjective dimension as noesis or the psychological act (e.g. perceiving, thinking, imagining) whereby one grasps the intended meaning. Consequently, meaning is also inextricably tied to the concept of intentionality. The meaning of something (the meant) is always contingent on how it has been constituted or determined by a subject in a subjective attitude (Karlsson, 1993).

According to Husserl, the world in which we live is the pre-given background or starting point of all experience: we take our world for granted and never question its existence (Karlsson, 1993). This pre-given world exists within the "natural attitude" wherein attention centres on the objects of consciousness and not on the constitutive acts of consciousness. To access the constitutive acts of consciousness, there must be an "alteration" of attention so as to allow the phenomenological attitude to emerge. Only within the phenomenological attitude can the mind reflectively attend to and decipher the directedness of consciousness--in other words, the underlying intentional focus of the experience.

Husserl's primary interest and consequently his primary contribution to the human sciences was the development of a rigorous scientific method which could reveal, through description, the real givenness, the essential structure of the phenomenon under investigation and with it, the structure of consciousness. In The Idea of Phenomenology (1970b/1907), he introduced

the phenomenological method and outlined the phenomenological reduction that he considered central to this method.

In phenomenological philosophy, the initial stage of the phenomenological reduction seeks to uncover the eidos or essence, the universal nature or structure, of the phenomenon. This reductive method is viewed as not merely a moving away from the natural world, but more fundamentally as a leading back to the origins of which our too hasty everyday thought has lost sight (Spiegelberg, 1965). In practice, the phenomenological reduction is a two-step process which involves "bracketing" the natural attitude and employing the technique of imaginative free variation. Bracketing is the attitudinal shift whereby the natural attitude of common sense, science and theories is held in abeyance or set aside so that one may be immersed in a phenomenological attitude. In turn, it is the phenomenological attitude that facilitates the disclosure and clarification of how given phenomena are constituted in and through consciousness. The process is actually an active openness to "what is" rather than simply a passive meditation. At the same time, attention is oriented toward that which, in the changing and varying examples, manifests itself as invariable and enduring (Kockelmans, 1967). Using the technique of imaginative free variation, the researcher, from within the phenomenological attitude, imagines many variations of the phenomenon, and then intuitively reflects to confirm or refute their plausibility or applicability or both. In the end, what remains is the previously secured essential structures and intentional functions of the phenomenon under investigation.

To distil and purify the reductive process even further, Husserl proposed a transcendental reduction requiring a bracketing of the phenomenological self so that what remained was a pure, transcendental ego distinguishable from the bodily organism and the psychological self (Spiegelberg, 1965). This radical

reduction to a pure transcendental subjectivity was consistent with his original quest to formulate an absolute "science of the spirit" (Ermarth, 1978, p. 207).

Husserl's investigations into the nature of transcendental subjectivity were extensive and underwent considerable refinement over time. His early efforts to conceptualize the primacy of transcendental subjectivity gradually led to an awareness of the unequivocal presence of the intersubjective realm. His early conceptualizations of intersubjectivity appeared in Cartesian Meditations (1967/1929), where he postulated that individuals experience the world including others as something "other than mine" and not as a private synthetic formation. He perceived the world as an intersubjective realm there for everyone, but accessible only in respect of its "objects". The fifth meditation is a thorough discussion of intersubjectivity in which he demonstrated how the transcendental ego constitutes other egos as equal partners in an intersubjective community. From the beginning Husserl posited that all knowledge of others is to some extent indirect. The other is given to us by way of "apperception" and not by direct presentation. Thus, we perceive a body other than our own as "there" rather than as "here". We immediately apperceive it as the body of an "alter ego" by way of an assimilative analogy to our own ego. At the same time, Husserl recognized that other egos constituted by the transcendental reduction were themselves transcendental and that together these egos formed a "community of monads" (Spiegelberg). It was not until his later years that we see evidence of a distinctive shift in his appreciation of the intersubjective realm. At that time, he moved from a solipsistic view to an intersubjective view and from a focus on the transcendental "I" to an appreciation of the transcendental "we".

The Crisis of European Sciences (1970a), published posthumously, reveals a significant transformation in Husserl's thought. He broadened the

original phenomenological method into what he called the "phenomenological-kinetic method" (Bell, 1990, p.215). Here the pure ego is recognized as a physical, sentient organism, as an embodied human being. Physical motility, or the power to act and the capacity for unmediated knowledge of the self, is seen as inherent dimensions of a living body. Specifically, the living body is viewed as the sole and absolute point of reference, as well as the "geometric centre of egocentric space" (p. 222). From this perspective, the existence of other persons as intentional objects is possible only through a decentralization of this egocentric space. As long as one remains in an exclusively egocentric perspective, genuine reciprocity is impossible. In the intersubjective world inhabited by a community of subjects, every individual consciousness from out of its own resources is intrinsically and essentially determined by its relations to other such centres of consciousness. The living body is also seen to possess a reflexive relation to itself that enables an imaginative awareness of the individual's own body--creating the possibility of the "objectification of oneself" which is a necessary condition for seeing others' subjectivity. Many of Husserl's later insights and reconceptualizations were taken up and further refined by the French phenomenological psychologist Merleau-Ponty.

In his last works, Husserl increasingly came to see intersubjectivity not as a problem confronting the solitary, solipsistic ego, but rather as a dimension or structure that at its very core characterized intentional life. Husserl placed the intersubjective community of conscious beings at the centre of his philosophical concerns and applied to that community such concepts as horizon, habituality and praxis that he had earlier applied to the isolated ego. By doing this, he discovered the constitutive role played by such factors as culture, tradition, common practice and especially history in the everyday life of the intersubjective community and thus indirectly in its life-world. Culture and the

individual are characterized as interwoven and co-constitutive, with culture understood as being manifested in the dispositions of the individuals and their institutions.

As his ideas evolved, Husserl moved toward a holistic perspective where the Lebenswelt, or life-world, is the sole, absolute foundation of all moral, scientific, philosophic and everyday practices. It is understood as a structure of meaning formed out of elementary intentionalities, the most elementary being the activities of the living body. Given the foundational nature of the life-world, it is imperative that its aspects, as well as the complexity of its interrelationships, be accounted for in the phenomenological descriptions resulting from phenomenological analyses.

The task of phenomenology was now to go back to the intentional origins, the meaning-structures of human experience. This required a phenomenological investigation of the factors that, over the ages, determine our culture and, hence, our life-world. As a result, increasing emphasis was placed on the importance of historical considerations. Consequently, it appeared that Husserl had moved away from his earlier conception of phenomenology since he now acknowledged a holistic, culture-relative and basically indeterminate view of reality.

Heidegger

As a student and protégé of Husserl, Martin Heidegger was well versed in both phenomenological philosophy and the phenomenological method. While Husserl endeavoured to formulate a scientific method capable of revealing the "whatness" or structure of consciousness, Heidegger focused his research on the nature or "way" of "being" of human existence. He viewed the exclusion of the dimension of Being from Husserl's phenomenological investigations as consistent with the long tradition of Western thought

originating from the early Greeks. There the seeds of the split between reason and the "whole person" had been sown and this, in turn, led to the gradual estrangement of modern humans from their own sense of Being (Barrett, 1962). Heidegger devoted his research to resolving this estrangement of the individual from his or her world. This effort, in turn, led to his central premise of the primacy of "being" and the inseparability of being from the world.

Heidegger's most important contribution to the human science movement is his conceptualization of the primary characteristic and basic state of human existence as a "Being-in-the-world". Human beings are not solitary or independent entities distant from nature or the world they inhabit. Rather, they are totally immersed and involved in their world. Each individual constitutes a field or region of Being which Heidegger called Dasein, "Being-there". Dasein and its world are essentially co-constitutive and interdependent. Thus, one's existence emerges both for oneself and for others, by and through one's involvement with the world. At the same time, it is one's personal existence that gives one's own world its meaning. Without an individual to reveal its sense and meaning, the world would not exist as it does.

In describing the basic nature of Being or Dasein, Heidegger created a distinctive and original language. He saw Dasein as "thrown" into the world, that is, thrown into a specific family, a socio-economic situation, a culture, and a historical era. He named the situation we find ourselves in to be the "facticity" of our life, that is, the actual facts we are given that include our genetic make-up, our familial and cultural situation and where we were born. Daily living was characterized as "everydayness" where we encounter other persons as das Man. Drawing upon the writings of Kierkegaard, Heidegger believed that only when we are in touch with our "beingness" and encounter our world in a genuine manner are we able to experience authentic existence. In contrast, our

everyday existence is considered to be inauthentic and indicative of our "fallenness", the modern predicament of being estranged from our own sense of being. This estrangement and neglect of being is most evident, for example, when one is preoccupied with idle-talk and busy-ness (Heidegger, 1962/1926). While it is important for human beings to strive to encounter self, others and the world in an authentic manner, Heidegger nevertheless firmly believed that the dialectical experience of inauthentic everyday life is a co-constitutional dimension of human existence and therefore cannot be ignored. By its very nature, inauthentic existence provides the catalyst and stimulus to seek out our potentialities for being.

Through his phenomenological investigations, Heidegger discovered that Dasein, the "entity which I myself am in each instance" (Heidegger, 1985, p. 152) included three modes of "Being-in-the-world": "being-in", "being-with" and "self-transcendence". Each mode exhibits a specific and particular way of being-in-the-world. Dasein, as "being-in-the-world", is not a self-contained, fixed entity, but rather a state of "being-possible" or becoming. Yet, given the "facticity" and "thrownness" of Dasein in its world, this being-possible is always a situated possibility with its own specific "potentiality-for-being" (Heidegger, 1962/1926, p. 184). Heidegger referred to the world of Dasein as that of "worldhood". As such, it does not signify a spatial container, but rather a sense of region (aroundness), of distance (near and far), and of directionality (orientation) (Heidegger, 1985).

Dasein as "being-with", is always already a being with others as "Co-Dasein" even when the other is absent and Dasein is a "being-alone". Thus, the worldhood of Dasein includes not only the surrounding world and one's own self, but also the Co-Dasein of others. For Heidegger, the ability to

understand the other occurs through the individual's encounter with the world where the other is present with me.

Dasein, as "self-transcendence", has the capacity to go beyond an individual's existence in search of the being-possible of this existence. This is not a search for a metaphysical substance, but for an awareness of the primordial relationship with the world of objects and of other persons as well as with oneself (Slaatte & Sendaydiego, 1984). Hence, Dasein is uniquely the only Being capable of being aware of its own Beingness. The modes of Being-in-the-world as conceptualized by Heidegger were later reformulated by Binswanger (1963) as Umwelt (environing world), Mitwelt (social world) and Eigenwelt (one's personal world).

Heidegger's phenomenological investigations into the nature of Being led to the discovery of several existential structures or existentiale which underlie human existence. He called these existential structures Befindlichkeit (state-of-mind or mood), Verstehen (understanding) and Rede (discourse). All three are equiprimordial and disclose the beingness of Dasein. State-of-mind, or mood, is foundational for it discloses the whole of Dasein's being in terms of one's "attunement to one's own world" (Gendlin, 1978-1979, p. 56). More specifically, it reveals how we are affected by our thrownness and how we "find" ourselves in given situations (Heidegger, 1985).

Understanding, as an existentiale, manifests itself in terms of Dasein's awareness of "something as something" (Heidegger, 1962/1926, p. 189), including an awareness of its own beingness and its potentiality-for-being. Heidegger called the capacity of understanding to move beyond itself, interpretation. With interpretation, however, understanding does not become something different, rather it "becomes itself", it makes explicit what is understood (Palmer, 1969). When the interpretation of understanding is

articulated, the essence or meaning of what is understood is expressed and asserted. As a derivative of understanding, assertion or the making concrete of understanding, allows the understanding to be passed along for further retelling and facilitates widening the range of mutual sharing (Heidegger, 1962/1926).

Through the existentials of discourse, the "existential-ontological foundation of language" (Heidegger, 1962/1926, p. 203), mood and understanding are made known. Mood is disclosed through intonation, modulation and tempo of the voice. Understanding is shared through all manner of discursive speech, i.e. from speaking, hearing, listening, hearkening, keeping silent to talking excessively, as well as other modes of shared communication such as written texts and works of art.

Heidegger's investigations into the Being of human existence led him to a new and novel appreciation of time. Time is described as intimately inter-related with the beingness of Dasein rather than outside of Dasein (as a kind of framework in which events take place). As such, Dasein temporalizes its own Being and in turn constitutes time (Kockelmans, 1990). Time actualizes the unity of one's life from birth to death and reveals the historicity of human existence. We are not born at some moment in general, but at a particular moment in a particular milieu. However humbly we enter the world, we also enter into a historical destiny (Barrett, 1962).

Because of its existential nature, Dasein is essentially unfinished and is always in a state of becoming. Thus, Dasein is distinctly future oriented as it strives to transcend itself and move toward its own "power to be" (Kockelmans, 1965). The realization of one's finitude, the possibility of one's own death, conjures up dread and a fear of nothingness. It also has the paradoxical power to free Dasein to experience itself as a personal "be-ing", i.e. that one can be only what is intrinsically possible given one's thrownness in the world. "Care" is

the existential-ontological term used by Heidegger to describe the primordial pull towards authentic living, the need to fulfil one's innate potentialities. Care is the call to conscience; to be and become all that we may be within the demands and confines of our circumstances. Care is the turning away from "everydayness" and becoming "resolute" in the pursuit of personal authenticity. For Heidegger, it is the "being towards death", the being towards absolute nothingness that jolts us into an awareness of the need to return to authentic living. The awareness of nothingness may result from the creeping anxiety that emerges during everyday life, through "thrownness" which brings us face to face with the very real possibility of death, or the natural attunement to one's inner sense of being and becoming. Because we are "beings-in-the-world", Care is also a call to encounter others fully and to engage in meaningful activities. In the end, Care is the resolute nurturing of one's true personhood, of making the most of our capabilities and our circumstances within the context of our lives.

Dasein's future orientation, as conceived by Heidegger, presupposes a reciprocal relationship between present and past. The phases of time are existentially inseparable in reality. Separation is possible only by applying the external framework of worldly clock time. In essence, the past, as "having been", is able to manifest itself only because there is a future. The future exists in a certain sense because it is the genuine completion of the past, while the present is that aspect of time where things are encountered or made present. For Dasein, time is uniquely experienced as a structural whole; a unity of past, present and future. This facilitates Dasein's sense of Self-constancy despite the constant changing of personal experiences (Heidegger, 1962/1926).

Heidegger's initial search into the nature of Being suggests that being, in and of itself, is not really a phenomenon but a more complicated, encompassing

and elusive dimension. It can never become an object for us as it is always in the process of becoming. To this end, it also became apparent to him that in order to investigate the full complexity of Dasein as an historical Being-in-the-world and to illuminate the dynamic structure of Dasein's being, phenomenology had to become hermeneutic. For Heidegger, phenomenology provides the means to describe specific phenomena and hermeneutic-phenomenology provides the means to contextualize and interpret phenomena in terms of their dynamic, lived structures.

Unlike phenomenology, hermeneutic understanding does not claim to be a presuppositionless apprehending of something presented to us (Heidegger, 1962/1926). While phenomenology seeks to bracket or set aside presuppositions and prejudgements, hermeneutics aims to acknowledge and explicate presuppositions, inherent prejudgements and traditions. Moving beyond the writings of Schleiermacher and Dilthey, Heidegger saw that understanding and interpretation are always rooted in something that has been grasped in advance. In this way, all understanding is based on pre-understanding. Heidegger conceptualized this pre-understanding as the "fore-structure" which includes fore-having, fore-sight and fore-conception. Fore-having is that notion of the phenomenon we have in advance. It is based on the context and anticipation of meaning we already carry with us. Fore-sight is that which we see in advance. Fore-conception, the conceptual notion we already possess, is a framework for our interpretation and enables us to grasp something in advance. Thus, from a hermeneutic-phenomenological perspective, the fore-structure of pre-understanding serves as the basis of our understanding of any given phenomenon. However, for a comprehensive understanding of the phenomenon under investigation, understanding includes not only an explication of its fore-structures, but also the explication of the "as-

structure" of interpretation, as well as the "meaning-structure" of the phenomenon. In the words of Bleicher (1980), the as-structure is the interpretation of something as something, the making explicit of what is already understood while the meaning-structure is the "upon-which" whereby the something becomes intelligible to us as something.

Heidegger's contributions to the human science movement furthers our appreciation and understanding of human existence. Through his hermeneutic-phenomenological investigations, he uncovered the essential structure of human nature as that of Being-in-the-world. The equiprimordial existential structures of mood, understanding and language or discourse were shown to disclose the nature of one's Being-in-the-world. The life-world was revealed to be inseparable from human experience and also the place where self, others and world are encountered. Time was conceived as future-oriented, thus highlighting Dasein's striving "to be". As well, the experience of time was seen to provide the connectedness of life-experiences and a sense of Self-constancy. In terms of human science research, Heidegger's investigations revealed the need for both phenomenology and hermeneutics--the former disclosing and describing the phenomena, and the latter contextualizing and interpreting them.

Merleau-Ponty

The writings of both Husserl and Heidegger played a significant role in the development of Maurice Merleau-Ponty's thinking and writing. Husserl's later ideas, which had been formulated in The Crisis, most notably his recognition of the foundational nature of the life-world, the lived-body, and the importance of intersubjectivity and language, became the cornerstones of Merleau-Ponty's own focus, i.e. to develop a phenomenology of the lived-body and of perception. As well, he expanded Husserl's meaning of intentionality to

include preverbal thought and the pre-personal dimension of bodily intentions and meaning (von Eckartsberg, 1986), and broadened Husserl's phenomenological method so that the essential structure of embodied lived-experience could be investigated and revealed. While Merleau-Ponty endorsed Heidegger's conceptualization of the existential realm of human experience and the unitary nature of Dasein as "being-in-the-world", his existential-phenomenological project moved in a different direction. For Merleau-Ponty, his focus of interest in his early works was the dialectical relationship of perception and the perceived world as the ground of human existence.

While Merleau-Ponty made many contributions to phenomenological research, his formulation of a phenomenology of the lived-body and of perception is unique. Furthermore, his phenomenological rendering of Gelb and Goldstein's celebrated case of Schneider, who suffered from "psychic blindness" as a result of a penetrating missile wound, is particularly relevant to the present study.

Merleau-Ponty's first important work, The Structure of Behaviour (1965/1942), offers a critique of modern psychology, in particular experimental psychology, Gestalt psychology and psychoanalysis. Here, he challenged modern psychology's fundamental limitations, and in doing so he moved towards his primary project of conceptualizing the philosophical primacy of perception and his fundamental discovery of the human body as an embodied-subject. In The Structure of Behaviour, Merleau-Ponty tried to establish that human behaviour cannot be reduced to its alleged parts and their movements; nor is it a thing or consciousness. Rather, human behaviour can be understood only in terms of its structure or pattern of relations (Merleau-Ponty, 1965/1942). Here structure is understood as the embodiment or representation of the matrix

of relationships of parts within the whole. Furthermore, these relationships are specifically dialectical in nature. In his later work, The Phenomenology of Perception (1962/1945), he extended his thinking to show that individuals are imbued not only with personal agency, but are also, in essence, embodied subjects.

In The Structure of Behaviour, three structures or orders of behaviour are identified and distinguished: the physical, the vital and the human. The physical order is based on physical systems, i.e. inert entities. Vital and human orders are fundamentally different from physical orders in that the relationships between the organism and its milieu are dialectical and carry intrinsic meaning or significance for the organism. However, within the vital order, signifying signs always remain as signals. It is only within the human order that signifying signs are able to become symbols. Furthermore, within the human order, the individual is endowed with the ability to transcend and this enables him or her to transform not only situations, but also the self. This ability to transcend, or go beyond, endows the individual with a capacity "to move beyond created structures in order to create new ones" (Mook, 1987, p. 179).

As Merleau-Ponty's investigations progressed, he began focussing increasingly on the primacy of perception as the foundation of human existence. For him, perception is not the reduction of human knowledge to sensation. Rather, it is "our presence at the moment when things, truths, and values are constituted for us" (Merleau-Ponty, 1964a, p. 25). More importantly, perception is seen as the privileged realm of human experience, the background from which all acts stand out (Merleau-Ponty, 1962/1945), as well as the primordial operation that impregnates sensible being with meaning (Merleau-Ponty, 1964b).

Merleau-Ponty's investigations of traditional natural science methods for the study of human behaviour revealed that before things can be pure objects, they are initially present in one's own existence accompanied by an ability to confront each of us in a natural and immediate way (Madison, 1981). Likewise, the human body, before being an object that can be conceptualized or treated conceptually as a physiological thing, is also an integral dimension of one's own existence. While Heidegger posited the inseparability and co-constitutionality of the individual and his or her world, Merleau-Ponty further defined this relationship and identified the lived-body as the primordial entity that embodies the individual's relationship with the external world. In essence, he re-established the roots of the mind in the body and in the world, and pointed out that it is only in "abnormal" cases where pathology is present, that body and soul appear as distinct entities or agents (Kockelmans, 1982).

Merleau-Ponty emphasized that the lived-body is not an object in and of itself. It is an embodied presence in a world which is already there for it. At the same time, perceptual consciousness is not absolute interiority or pure presence of the self to itself. Rather, it is one's bodily presence in and awareness of the world. Thus, the perceiving subject is fundamentally a worldly subject as well as the foundation of human existence. More specifically, the notion of the embodied subject is indicative of three founding features: the subject is inescapably in a world, it is an active agent, and it constitutes a perceptual field that has an orientational structure (Taylor, 1990).

The orientational structure of the embodied subject provides the ground for all spatial and temporal judgements, for accessibility or restriction, and for a sense of security or threat. It is a relational marker or anchor for all personal experience: past, present, real, imaginary, and even the possible. As well, all human judgements, values, understanding and interaction with others are

formulated in terms of this orientational structure, i.e. the relevance to who we are, how we are, and where we are at this point and place in time. It is only in those moments when we lose this orientation, when we do not know where we are, that we lose the thread of the world and our perceptual field no longer serves as our access to the world.

As a knowing-body, we possess the power of being able to turn back on ourselves, that is, of reflecting on our own self. In this situation, the body is neither a subject nor an object. Rather it manifests an ambiguous union of the two, a reversible circularity that is conceptualized as the "flesh" by Merleau-Ponty in his later writings. The prototype of the reversibility thesis derived from Sartre's (1956) understanding of human touch. For Sartre, touching and being touched were essentially different orders of reality--therefore a dualistic conception of embodiment remained. By contrast, Merleau-Ponty understood touching and being touched as different aspects of the same underlying unity, one's own body, that is, different sides of the same coin. In the words of Dillon, perception of the thing or the body as touched requires de-centring, so that the body takes on an "identity-within-difference" (Dillon, 1990). At a foundational level, the body is an exemplar of the sensible domain. As flesh, it serves as a unifying agent between senses and relates to the world in terms of flesh to flesh paralleling the model of one hand touching the other.

Merleau-Ponty's concept of the Other, that is, of alterity, moves beyond Husserl's conceptualization. For Merleau-Ponty, the Other is understood in terms of a differentiation from self, as part of an "identity-within-difference" structure of the reversibility thesis (Dillon, 1990) and entails a fundamental de-centring from one's egocentric self. Inherent in his conceptualization of alterity is the fact, as mentioned previously, that things and others are understood simply because they are initially an integral dimension of one's own existence.

Therefore, the ability to recognize and know others extends from one's awareness of one's own self. However, the reversibility of roles between self and Other is impossible in a literal way, for seeing and being seen are divergent and non-coincidental, despite the fact that looking presupposes being visible. I am able to see the Other and the Other is able to see me, but I do not experience my being seen as he or she does--thus creating the asymmetrical aspect to the reversibility theory. In addition, Merleau-Ponty demonstrated how reflection and language embody the concept of reversibility. In reflection I become Other to myself. Through language, the systematic linguistic organization refers back to the self and serves as a means of detachment or separation from the self. Merleau-Ponty's thesis of reversibility thus articulates the notion of transfer of corporeal schema beyond the idea of "pairing" originally described by Husserl, and leads to a potentially more comprehensive understanding of the intersubjective realm.

In Merleau-Ponty's later years, a transformation in his thinking occurred. An Unpublished Text: A Prospectus of His Work (1964a) is a personal account of this evolution. The perceived world is seen in terms of a universal style shared by all perceptual beings. The lived-body provides access to both virtual and actual space as well as purveying our expression in the world. The lived-body thus presents a visible form of our intentions, and as a perceiving subject, "it undergoes a continued birth so that at each instant it is something new" (p.7).

In Signs (1964b), Merleau-Ponty eloquently presented his later perspective of the intersubjective realm. Recognizing others occurs when some sign of the Other's presence to one's self is deciphered, since each and everyone of us hold within our own selves a model of being human. Likewise, whenever I try to understand myself, the whole fabric of the perceptible world including the Others immersed in it is found to be inseparable. The perceptible

world, by its very nature, extinguishes separateness and the sense of distance from the Other simply because it accommodates everyone. Finally, Merleau-Ponty offered the idea of a single, universal history for humankind. He stated that all cultures can be compared and placed under a common denominator. The connecting link between cultures is a "permanent, harmonious thought of the plurality of beings who recognize one another as 'semblables', even when some seek to enslave others and who are so commonly situated that adversaries are often in a kind of complicity" (1964a, p. 10). Here one senses the evolutionary process through which Merleau-Ponty moved from an original exploration of the inadequacies of natural science research methods for the human sciences toward a principle of a universal ethics underlying human existence.

When reflecting on the contributions of these seminal scholars of human science research, the evolving nature of their writings becomes quite evident. As does human understanding, their offerings are in the process of becoming. Individually there may be omissions and debatable conclusions, yet when viewed holistically each, in their own way, has contributed to the building of a solid human science research paradigm.

All were profoundly dissatisfied with the natural science research methods employed by contemporary researchers who explored human behaviour and experience. In response, each philosopher conceptualized and formulated a rationale for a legitimate human science approach, and each formulated a research method to investigate human experience and human living. All recognized the Lebenswelt, or the life-world, as the ground of human experience. Dilthey and Heidegger, in emphasizing the temporal and historical features of human existence, formulated a hermeneutic approach. This approach extended the original descriptive method in order to facilitate a fuller

understanding of the complex dialectical nature of human existence within the life-world. Husserl and Merleau-Ponty, coming from a more traditional philosophic background, focused on the phenomenology of the individual within the life-world. However, as their thinking matured, they too embraced a holistic appreciation of human existence. In the end, their original themes and concepts were shown to be co-constitutive and integral to human life and the human condition. Husserl (1970a) eventually discovered that the life-world was the sole and absolute foundation of all moral, scientific, philosophic and everyday practices, and thus of human culture. Merleau-Ponty (1964a), also finally regarded the human condition as part of a universal history common to all cultures.

These philosophers of human science have provided us with a foundational understanding. If we equate their conceptualizations to the building of a house, we will see that the footings, cornerstones and also the foundation walls on which to construct a home have been provided. To take our analogy further, we may view our building as the construction of a home and not a house, that is, a dwelling place for human existence and for human science research.

Foundational Concepts for an Existential-Phenomenological Approach

Foundational concepts are, in essence, the building blocks we use to build our rationale for using a specific research approach and method. In existential-phenomenological research, where we study phenomena of human living, foundational concepts represent the constitutional dimensions of human existence. In our exploration of family members' experiences of living with a head injured person, the foundational concepts of intentionality, the life-world, Being-in-the-world, temporality, embodied-subjectivity, intersubjectivity and language are particularly relevant. Guided by the writings of Dilthey, Husserl,

Heidegger and Merleau-Ponty, we will present a brief description of the above mentioned foundational concepts.

Intentionality

For those who embrace a human science research approach, the conscious realm of human experience is accessed by investigating the intentional dimension of human consciousness that forms its underlying structure. Our understanding of intentionality focuses on Husserl's reformulation of Brentano's original concept of intentionality. Brentano postulated that consciousness is always a consciousness of something; it is always directed towards something. Consciousness is thus the medium through which phenomena show themselves or are revealed to us. Husserl determined that intentionality, as the essence of consciousness, is an integrative process. It is the link between the subjective dimension, with its actual intentional acts of consciousness (noesis), and the objective dimension that includes the intended objects of consciousness (noema). Husserl further demonstrated that his phenomenological method, by its ability to disclose the objective dimension of intentionality, was in effect able to reveal or make intelligible the full nature of consciousness (i.e. subjective and objective dimensions) of a given phenomenon. Merleau-Ponty (1965/1942) broadened the notion of intentionality to include behaviour and the whole bodily being of the person. According to him, we as bodily beings, are always in relation to that which is beyond us, i.e. others and world. We are always in relation to and directed towards the world in which we live. Again, we see the indissoluble unity or inseparability of Being and the enviroing world. It is apparent that a phenomenological understanding of consciousness breaks radically with more traditional views of consciousness as a worldly entity in that it conceives of consciousness as inherently intentional and therefore meaning-bestowing.

Furthermore, all behaviour is seen as intentional and significant. In our study, the consciousness and behaviour of our family members will be seen as intentional and meaningful.

Life-world

Human existence is first and foremost embedded within the "life-world"--acknowledged to be the foundation of all human experience. It provides the ground for the dialectical relationship between the organism and its milieu (Merleau-Ponty, 1962/1945). Furthermore, it is the pre-given background and starting-point of all human strivings. It manifests itself in the natural attitude (Husserl, 1967/1929) and is experienced through our day-to-day living. We have access to the life-world of individuals by looking at their "expressions of life", the objectifications of their experience, i.e. behaviours, gestures, tones of voice, verbal and written expression (Dilthey in Mueller-Vollmer, 1985). The advent of a traumatic head injury in a family member inextricably alters the family's life-world. In a matter of hours, their everyday, taken-for-granted world is thrown into a quandary. The existential ground on which their familial life is based may no longer feel secure or reliable. In fact, the family may suddenly feel that life itself is in jeopardy.

Being-in-the-world

From Heidegger (1962/1926), we learn that human life is inseparable from the world in which the individual finds him or herself. As such, each person is a "Being-in-the-world" or Dasein. The concept of Dasein exemplifies human existence as a field or region of being which is experienced as "itself" at a particular moment in time and space. Dasein is inseparable from all that exists in the environing world. More precisely, individual and world share a mutual and reciprocal relationship where each partakes in the meaning to the other. Traumatic head injury disrupts a person's conscious life. Depending on

the severity of the injury, consciousness may be affected momentarily, temporarily or permanently. When consciousness is affected, so is one's sense of Being and consequently one's sense of Being-in-the-world. Though the field or region of Being is altered for the head-injured person, it still remains that person's field of Being, and the altered relationship to the world is still that person's relationship to and within the world. For the family as a whole, the situation is different. It is the matrix of relationships within the family constellation and with the enviroing world that is affected. In turn, individual family member's sense of Being may also be altered.

Temporality

From an existential-phenomenological perspective, "temporality" is the pre-eminent characteristic and distinguishing feature of human existence. Dilthey conceived of time as a unifying structure where past, present and future are interrelated and interdependent (Dilthey in Mueller-Vollmer, 1985)). The past is that which has been completed, and the future embodies that which is possible. The present holds a special position because it fills each moment of time with reality. Heidegger furthered our understanding of temporality by focusing on the intimate relationship between temporality and Dasein (Heidegger, 1962/1926). For Heidegger, time actualizes the unity of one's life, contributes to one's sense of self-constancy, and reveals the historicity of human existence. Heidegger's view of temporality is somewhat novel in that it carries a distinctive future orientation. Due to its existential nature, Dasein is always incomplete and in a state of becoming. However, the awareness of the possibility of one's own death (i.e. the ultimate possibility of life) carries a paradoxical power. It breeds fear and a dread of nothingness. Yet at the same time, the fact that one will eventually die has the capacity to free one to do and become what one can be. In reality, there seems to be an existential pull

towards the future, encouraging some sort of self-actualization no matter what the circumstances.

For the person who sustains a traumatic head injury, time may literally stand still, especially if the period of unconsciousness is more than transient. As well, a temporary or even a permanent loss of the ability to experience the ongoing nature of time may occur, and the future including future possibilities, may become clouded, or truncated, or both. At its deepest level, traumatic head injury brings the individual, and consequently the family, face to face with the possibility of death. For the individual, his or her true existence may actually be brought into question. For the family, the experience of temporality may be altered because of the dramatic change in everyday routines and priorities. As well, future dreams and aspirations may be compromised or even shattered. Because the effect of the consequences of traumatic head injury varies among individual family members, so too will individual experiences of the flow of time which, in turn, may also affect the family's temporal synchronicity.

Embodied-subjectivity

Phenomenologically, the body of a human being is not simply a psychophysical entity. The later Husserl (1970a) demonstrated that the human body is a "lived-body", one that is the sole and absolute point of reference and geometric centre of the individual's egocentric space. His notion of the lived-body was further defined and elaborated by Merleau-Ponty (1965/1942) who situated the lived-body as the relational centre within an orientational structure of human experience. More precisely, he showed that the lived-body is an "embodied-subjectivity-in-the-world" capable of personal agency and imbued with a capacity for self-awareness and self-knowledge. For Merleau-Ponty, self, others and world are experienced through a unique dialectical interrelatedness that he identified as the "flesh". This notion of bodily flesh captures the

paradoxical and reversible nature of human flesh as having the capacity to perceive as well as to be perceived. Furthermore, the reversible nature of human flesh serves as a template for our experience of the realm of intersubjectivity (the world of self and others) and of language or expression. Merleau-Ponty pointed out that only in "abnormal" cases where pathology is present, do body and soul or mind start to function as two distinct entities or agents. Through his detailed phenomenological descriptions of the case of Schneider, we are given a compelling appreciation for the plight of a head-injured person. In brief, Merleau-Ponty (1962/1945) went beyond the explanations of traditional neurology and psychology and showed that Schneider's difficulties are more than defects of the visual, tactile and motor systems and even of his capacity for abstraction. At heart, we see a disruption of the expressive dimension which leads to a more primary disturbance of his power of projection. In turn, his ability to interact with his world is severely compromised. Merleau-Ponty thus serves as a foundational contributor for this present study of the impact of traumatic head injury on family life.

Intersubjectivity

Human life is essentially an experience of co-existence. At its deepest, it is a truly intersubjective experience, a dialogical affair. Initially, the notion of "intersubjectivity" was conceived simply in terms of the interconnectedness of human experience. Beginning with Husserl's original formulation (Husserl, 1967/1929), intersubjectivity was seen as an outgrowth of his emphasis on transcendental subjectivity. Emphasizing the subject as the source of all objectivities, Husserl posited that the transcendental ego constituted other egos indirectly by means of apperception. By assimilative analogy, the body of the other is apperceived as an alter ego. However, this early interpretation of intersubjectivity remained at the level of a community of monads. As Husserl's

thought matured and he recognized the primacy of the living body and its centrality to human existence, he realized that awareness of the existence of other persons occurred through a de-centring of egocentric space. Finally, the intersubjective realm was described as a dimension or structure characterizing intentional human life at its very core and was the basis for the interwovenness of individuals and their culture. Heidegger's formulation of intersubjectivity was consistent with his notion of Dasein as a Being-in-the-world. In terms of the Mitwelt, the world is the common denominator and place of encounter between self and others. Merleau-Ponty deepened Husserl's later understanding and formulated his theory of alterity or otherness based on the primacy of perception. According to his theory, we know others because we know our own selves. In essence, we carry within us a template of being human. Our perception of others occurs because of the unique dialectical capacity for reversibility contained in human flesh. Realizing the existence of others involves a de-centring of the self, which in turn facilitates recognizing an "identity-within-difference" (Dillon, 1990, p. 80). Thus, the concept of the intersubjective realm evolved from the notion of a community of monads to that of individuals co-existing and co-constituting a shared life world. In general, family life can be seen as the ground from which all shared human existence arises. Family members share living-space, time and history, as well as hopes and dreams for the future. Here, individual lives are intimately interwoven within the matrix of family life which, in turn, is embedded in a broader social and cultural world. An existential-phenomenological approach enables us to study the effects of a traumatic head injury suffered by one family member on the interrelational and interactive dimensions of family life.

Language

Language, as a phenomenon of human existence, is indicative of our intersubjective co-existential nature in a most profound way. It is more than a means of communication; it is an interactive endeavour. As such, language is never mine alone; nor is it something solely given or thrust upon the Other(s). Words, gestures and movements are not chosen in isolation of the Other. Rather, the other leads one toward an utterance and co-determines its propriety.

From Heidegger (1962/1926), we learn that discourse is the existential-ontological foundation of language. As one of three existentiale, discourse is the means by which Dasein expresses its mood, or attunement to its world, as well as its understanding of Being-in-the-world. Discourse also expresses Dasein's intentional nature because talking is always about something. More importantly, discourse exemplifies the relational nature of Dasein. In discourse, "Being-with" becomes an explicitly shared experience.

Merleau-Ponty (1962/1945) presented a similar view of language, but from the perspective of a phenomenology of expression that, in turn, is grounded in his phenomenology of perception. It is through the lived-body that expression and language come about. Words are not simply containers for ideas or thoughts, and speech is not simply a sign of a thought. Speech and thought are "intervolved" and carry meaning. The spoken word is a gesture whose meaning expresses the individual's experience of the world. Expression brings meaning into existence; it makes an idea or a thought one's own. Moreover, it makes that which was secret public and visible, and therefore allows access to and from others. Language facilitates a living relationship with others.

While both Heidegger and Merleau-Ponty recognized that the essence of human language is more than chains of words conveying thoughts, Merleau-

Ponty, through his concept of embodied-subjectivity, recognized the inseparability of the body from its thought, and proposed that it is always the body that speaks. Language articulates itself according to the demands of the world it finds itself in. Because the lived-body and the world are inseparable, the meaning structure of one's language reflects the meaning structure of our world. Consequently, existential-phenomenological research values all manner of discourse. Because language is inherently a dialogical endeavour, it has the capacity to capture and express the shared qualities of family living and family interaction. For the purpose of our study, the language expressed and shared between family members will be of utmost importance. It will also provide the primary data base upon which this research project will be based.

The discussed existential-phenomenological concepts provide the foundation for our exploration of the phenomenon of traumatic head injury as it pertains to family living. We will explore how the trauma, arising from the disconnection of cerebral neurons and neural pathways, permeates all manifestations of human life, and affects the interrelationships of self, others and world. Furthermore, we will see that such a disconnection can disrupt even the most fundamental and primary dimensions of the human being.

Rationale for an Empirical-Phenomenological Research Method

Existential-phenomenological research rests firmly on the larger foundation of the human science paradigm. It is not antithetical to mainstream psychological research which adheres to a natural science paradigm. Both hold to basic scientific tenets, namely the need to be methodical, systematic and rigorous in order to comprehensively investigate the phenomenon at hand. However, the paradigms diverge on epistemological grounds. In turn, this divergence determines their approach to reality, as well as to their conception of basic research criteria.

Existential-phenomenological research focuses on the unique nature of the human condition. As such, it recognizes the inseparability and co-constitutionality of person and world. It seeks to disclose the nature or whatness of this interrelationship, i.e. human experience. By contrast, mainstream psychological research views the world, including human beings, as composed of determinate objects that are joined and determined by external relations. Consequently, mainstream research primarily looks at external objects that can be observed. It aims to decipher the why or how of the object(s) investigated.

Psychology as a descriptive science, initially proposed by Dilthey at the turn of the century, maintained that human experience was inseparable from human behaviour. Underlying this inseparability of subjective and objective realms of human experience is the fact of intentionality, i.e., that human consciousness is always directed towards something. Intentionality can only be experienced directly; it cannot be explained in terms of external, causal relations. It is only through the phenomenological reduction, a unique feature of the phenomenological research method where prejudgements and assumptions including scientific theories are "bracketed" and held in abeyance, that the essential features of consciousness and intentionality may be revealed. Description, both written and verbal, is a way the phenomena of human experience and behaviour may be accessed and subsequently analyzed. Written and verbal descriptions, according to Dilthey, are the "objectifications of experience", the means by which lived experience is made intelligible to others.

Knowledge of the phenomenon under investigation is revealed through the understanding of the nexus, or matrix, of constituent features and their inter-relatedness. From a human science perspective, the individual is seen to be interrelated and interwoven with his or her world, and mind and body are seen

to co-exist as embodied subjectivity. Consequently, all individuals are understood to be inter-dependent within a cultural world; they are embodied-subjects-in-the-world.

When exploring the lived experience of a phenomenon, we ask research subjects to describe in detail everyday experiences exemplary of the phenomenon under investigation. Here, the embodied expressions of the subject, the gestures, verbal expressions, tones of voice etc., become the raw research data. The phenomenological reduction enables us to return to the world of actual experience which is prior to the objective world (Giorgi, 1984). More specifically, it allows us to regard everything that is given in experience precisely as it appears in consciousness, and to highlight the themes critical to our understanding of the phenomenon. While the disclosure of the phenomenal structure reveals the essential and invariant constituents within the phenomenon, it is the explicitation of the existential constituents embedded within the structural configuration that illuminates the ongoing, dynamic magnitude of the phenomenon.

In summary, if we wish to effectively investigate the phenomena of human experience, we must select a research method that allows us to address and grasp the complexity and depth of human living as it manifests itself in a variety of situations and contexts. That is, if we wish to investigate what it is like for family members to live with a head-injured person, we must choose a research method sensitive to the psychological meaning of traumatic head injury. In particular, it must be responsive to alterations in the family's life-world, the temporal unfolding of the phenomenon, the intersubjective realm of family living, and especially to the existential dimension of being human. For it is here in these uniquely human dimensions that subtle and profound changes are particularly problematic. To this end, we believe that an existential-

phenomenological research approach that is sensitive to the life-world of the subjects, honours the phenomenal realm, and is able to reveal the inherent structure or essence of the phenomenon (Giorgi, 1984) is ideally suited to an investigation of the experience of living with a head-injured person within a family context.

Chapter III

LITERATURE REVIEW

Research literature focusing on the phenomenon of traumatic head injury can be found in a diversity of disciplines and orientations. Originally a concern for neurosurgery and physical medicine, traumatic head injury now also occupies a distinct position of concern within the disciplines of neuropsychology, nursing, social work and medical family therapy. The following literature review gives some semblance of order to a prolific but disparate body of information. The primary sections focus on mainstream literature, the transitional position of Kurt Goldstein to traumatic brain injury, and the existential-phenomenological approach to tragedy, traumatic brain injury and family-living research. The mainstream literature is organized under the headings of theoretical and applied models, studies of head injury and the family, observational/clinical studies, quantitative and qualitative studies. The transitional position of Kurt Goldstein, linking mainstream and existential-phenomenological literature, is discussed in terms of Goldstein's organismic theory and his theory of traumatic brain injury. The section on existential-phenomenological literature presents Merleau-Ponty's foundational contribution to the study of traumatic brain injury, the phenomenology of tragedy, and a recent existential-phenomenological study of the experience of head injury. The chapter concludes with an overview of phenomenological theory and research on family life, a summary of the dominant issues and a description of the research study.

Mainstream Literature

The section on mainstream literature is divided into three subsections that reflect the diversity of interests and conceptual approaches contributing to our understanding of the phenomenon of traumatic head injury. These

subsections include theoretical models, applied models, and studies of traumatic head injury and the family which includes clinical and observational studies as well as quantitative and qualitative studies. A critical evaluation of mainstream literature concludes the section.

Theoretical Models

Brain Functioning and Theories of Recovery. Physicians treating severely head-injured patients cannot change the primary damage that occurs at the time of injury. Therefore, prevention of secondary damage--hypoxemia, hypotension, anemia, intracranial hematoma and increased intracranial pressure--must begin at the accident site with intensive treatment and rapid transport to a trauma centre. This must be followed by sophisticated monitoring and intensive care in order to maximize the potential for a positive outcome (Dacey & Winn, 1984).

The human brain is a wonderful and mysterious organ. Although the general rule is that the duration of coma or post-traumatic amnesia predicts the severity of residual brain damage, there are numerous exceptions. Occasionally a patient, whose lengthy coma predicted severe damage, will enjoy a remarkably good return to psychosocial competence while others, following what seemed to be a mild injury, suffer severely debilitating mental changes (Lezak, 1989). For this reason neurosurgeons, the professionals families often meet first, are usually very reluctant to offer a prognosis, saying that the injury is "too fresh". Psychiatrists (physical medicine and rehabilitation specialists) are usually also guarded. However, because the latter are actively involved in the rehabilitation process, they tend to be more optimistic and realistic in their assessment of the potential for recovery.

Recovery from head injury proceeds in an orderly fashion through various critical phases once the acute medical stage stabilizes. Following the

resolution of coma and post-traumatic amnesia, a prolonged phase of recovery begins. This is the time when impairments to higher cortical functioning often appear (Long, Gouvier & Cole, 1984).

Theories of recovery from traumatic head injury, while controversial at times, nevertheless provide the rationale for physical and cognitive rehabilitation strategies. Structural and neurophysiological models focus on the restoration of nerve fibre functioning, while neuropsychological and neurobehavioural models focus on the resumption of higher cortical functioning. Theories of recovery of function, in combination with clinical observations, have been used to develop a stage model of recovery from head injury (Moehle, Rasmussen & Fitzhugh-Bell, 1987). The stages typically range from coma to purposeful and appropriate behaviour. This includes (a) an early stage where simple sensory awareness and gross motor functioning return; (b) a middle stage requiring highly structured cognitive prostheses and rehabilitation to help increase comprehension, orientation and resumption of new learning; and (c) a final stage where greater independent functioning is facilitated by a gradual withdrawal of environmental supports or structures that have been established in the middle stage. The stage model of head injury recovery is a major guide for professionals and figures prominently in the lives of the families and special caregivers of the head-injured. Knowledge of the stages gives families markers and guideposts to watch for as well as indications of progress. Likewise, those who are unfamiliar with the stages will, in retrospect, be able to identify their occurrence. Typically, recovery of the head-injured person is usually a shared journey with the family. Each accomplishment, no matter how small, is a reason for celebration and a stepping stone to the next accomplishment.

Theory of Cognitive Adaptation to Threatening Events. How individuals respond to and live with threatening events figures prominently in both formal

research and popular literature. Taylor (1983), in her study of women suffering from breast cancer, proposes a theory of cognitive adaptation to explain how these women and their families are able to achieve a successful quality of life despite adversity. Her theory is based on the premise that successful adaptation in the face of a threatening event is related to the successful resolution of three basic themes: a search for meaning in the experience; an attempt to regain mastery over the event in particular and over one's life generally; and an effort to restore self-esteem through self-enhancing evaluations. According to Taylor, the critical feature in the successful resolution of the three themes appears to rest on the individual's ability to sustain and modify "illusions", which she defines as the ability to "look at known facts in a particular light" (p. 1161). The results of this study show the power of cognition to readjust and reframe situations and experiences, and consequently, their potential usefulness in clinical situations.

Family Process Models of Dealing with Stress. Process models give a sense of how families cope with normative and para-normative stressors and changes to family life. As well, they alert us to patterns of family functioning that either help or hinder families as they face a wide range of anticipated or unexpected events.

The Double ABCX Model of Adjustment and Adaptation (McCubbin & Patterson, 1983) and the related Circumplex Model (McCubbin & McCubbin, 1989) appear to be germane to a discussion of families coping with stress and tragedy in the context of a closed head injury. Reuben Hill (1949) first presented the ABCX Model of how families cope with stress. This model emphasized the disorganizing potential of stress and suggested that the extent of disorganization or crisis (X) on a family was related to the nature of the stress (A), the family's definition of the event (C), and the family's resources (B).

McCubbin and Patterson (1983) enlarged the model into the Double ABCX model to include the family's post-crisis behaviour that becomes part of an interactional process of adjustment and adaptation phases.

The notion of family coping patterns and styles, as presented in the process models (McCubbin and Patterson, 1983; Hill, 1949) occupies an important role in the larger picture of head-injury rehabilitation. However, the potential complexity of impairments, combined with the chronicity of the sequelae, make predicting adequate family coping extremely difficult. Theoretical models based on typologies and organizational structures (Lewis, 1986; McCubbin and McCubbin, 1989; Rolland, 1987) appear more effective in addressing the complexities of impairments following traumatic head injury. Furthermore, they may help clinicians and service providers maximize the fit between patient and family needs and appropriate interventions.

McCubbin and McCubbin (1989) formulated a family typology model, called the Circumplex Model, that identifies three distinctive family functioning schemes: regenerative, resilient and rhythmic. This model, based on the interaction between the dimensions of flexibility/rigidity and the dimensions of separateness/connectedness, describes the typical or customary ways family members interact with self, others and community, and negotiate problems. A typical organizing feature found in regenerative families is their effort to maintain a sense of family integrity as a means to endure and deal with hardships, stressors and strains. Resilient families cope with and recover from difficulties depending on how they accommodate dimensions of unity and change within the family structure. Rhythmic families deal with difficulties and stressors by using customary patterns of establishing and valuing predictability and stability.

Lewis (1986) presents a different theoretical model that focuses on the relationship between normative and severe stresses and the family's organizational structure. He posits that well-functioning families, in comparison with dysfunctional and severely dysfunctional or chaotic families, possess a degree of flexibility within their organizational structure. This, in turn, facilitates the development of closeness and a capacity for psychological intimacy, while also encouraging a sense of separateness that becomes the anlage for individuation and autonomy. When the balance between attachment and separateness is heavily skewed, the family lacks the means to accommodate variance and ambiguity arising from normative stressors. This has the potential to tip the scales and set the family off-balance when stressors accumulate or a traumatic stressor appears.

Rolland (1987) proposes a typological model of chronic illness highlighting the functioning of the system created by the interface of the family and the illness. He identifies the interactive relationship between types of illness, time phases of illness, family functioning, as well as the health-care team's relationship with the patient and his or her family. From this perspective, illness is understood as a psychosocial phenomenon that includes its own "illness life cycle" (p. 146). Grouping illnesses according to four basic categories--onset (acute versus gradual), course (progressive versus constant versus relapsing/episodic), outcome (fatal versus shortened life-span versus non-fatal) and incapacitation (present versus absent)--provides a typological foundation on which to investigate the other interactive dimensions critical to family functioning over the course of an illness. To this typological matrix, Rolland adds the temporal nature of the illness in terms of crisis, degree of chronicity and terminality. While these phases include distinct characteristics and tasks that must be attended to, they also tend to overlap, so that critical

transitional periods emerge. Thus, the temporal dimension of illness adds to the complexity as it interacts with the family life cycle as well as the life cycle of individual family members. Clinical implications for such a typological model include increasing clinicians' awareness of chronic illness in psychosocial terms, and helping clinicians think longitudinally in order to appreciate the ongoing process of chronic illness defined by its landmarks, transition points and changing demands. In addition, awareness of an illness time line allows clinicians and families to gauge and plan normative developmental transitions and tasks within the demands and limitations of the illness. In terms of research, Rolland posits that the typology and time phase matrix provides a framework from which to generate and test hypotheses about the relationship of different components of family or individual functioning to the course of the disease with its different types and phases of illness. In the end, he suggests that such a typological model moves us closer to addressing a more comprehensive understanding of the broader concept of illness within the family system.

Applied Models

Rehabilitation (physical medicine) and family therapy interventions offer practical ways to help survivors and their families deal with the consequences of traumatic head injury. Contemporary rehabilitation programs recognize the need for a wide complement of therapeutic disciplines and for the particular need to provide some form of specialized cognitive retraining. Service delivery has evolved from an individual symptom focus to an interdisciplinary model, to a more recent trans-disciplinary model where therapists transcend discipline boundaries (Rolider & Garner, 1992). According to Horton & Miller (1984), there are presently two primary paradigms for treating brain-injured clients in North America: (a) a holistic remedial approach with a fixed curriculum treatment that

provides every individual with the same instructions and training in perceptual, cognitive and interpersonal domains (e.g. Ben-Yishay et al, 1985), and (b) a tailored treatment approach where specific deficits are diagnosed and targeted for treatment (e.g. Horton & Miller, 1984).

Of interest to this study are the rehabilitation services provided for families and significant others of head-injured individuals that are part of a continuum of services. According to Vogenthaler (1987), a holistically-oriented rehabilitation program must include integrated services for the patient's family and significant others because the injury and subsequent disabilities may cause denial, guilt, depression, frustration and anger in family members, which in turn, will have an effect on the patient's potential for optimal recovery. Furthermore, these services must be relevant to each stage of recovery and to the stress patterns that emerge.

To date, little documentation of therapeutic intervention models specifically used to help families coping with the after-effects of head injury is available. Zarski et al. (1987) recommends a structural systems approach based on Minuchin's initial work with families suffering from persistent psychosomatic complaints. Ridley (1989) presents a different perspective based on a transactional theory of stress and coping originally formulated by Lazarus and his colleagues. A transactional approach employed in a rehabilitation setting aims to assist the family in "value restructuring". This helps the family to redefine the experience as embodying a potential for growth instead of only being seen in devastating terms. It also helps the family reinterpret the condition and ramifications of head injury in order to integrate recovery into their own personal lifestyle.

Studies of Head Injury and the Family

Research into the effects of traumatic brain injury on family living and functioning is comparatively new, mainly because it is only recently that individuals have survived serious head injuries and have recovered enough to be able to return to their family environment. Specific accounts of the plight of families living with a head-injured person began to appear in the 1970s. Empirically-grounded research soon followed and has continued into the present. In recent years, several family research studies have incorporated qualitative analytic dimensions in order to provide more comprehensive accounts of the difficulties faced by families of head-injured persons.

Observational and Clinical Studies. The first accounts of family difficulties following traumatic brain injury were based upon the results of support group interactions for spouses and mothers (Romano, 1974; Lezak, 1978). Romano provided a social work perspective whose central focus was long-term family denial of the general severity and impairments caused by traumatic head injury. Family denial of the severity of the situation often leads to grave repercussions in family functioning and patient adjustment. In addition, it tends to unfairly perpetuate patient denial of reality and, in turn, may contribute to depression.

Lezak (1978) presented a different perspective in her landmark article on the "characterologically altered patient". Here, the focus was on an increased sensitivity and appreciation of the plight of family caregivers, in this case spouses of male veterans. As a result of extensive clinical observations, she provided a detailed portrayal of the cognitive, psychological and social impairments faced by patients and their families and highlighted the primary caregiver as the one who carries the brunt of the burden. Lezak stressed that families need access to information and support; need to know that anger,

frustration and sorrow are natural emotions under such circumstances; and need to deal with role changes and conflicts along with the related shifts in responsibility. In a follow-up article she described more fully the psychological implications of traumatic brain injury for the patient's family (Lezak, 1986). The psychological sequelae of severe traumatic head injury are presented to show how they affect behaviour in general and social behaviour in particular. Problem areas are identified as: impairment of new learning in terms of speed and capacity that is often compounded by defective retrieval of information; impaired capacity for control in terms of regulation and adaptation of complex behaviour; impaired modulation of cognitive activities shown by conceptual rigidity and stimulus-boundedness; and impaired modulation of emotional reactions observed as increased lability, temper outbursts or flattened affect. Additionally, difficulty with self-monitoring or self-correcting hampers learning by experience. Lezak very aptly described the implications for the above deficits as a "deterioration of social graces" (p. 242) that lead almost inevitably to continuing social dependency, especially on their immediate families. Lezak's writings are grounded in her own clinical neuropsychological experience of working with individuals and their families and specifically with spousal support groups. They show a fine-tuned sensitivity and appreciation for the plight of both the head-injury survivor and the family.

Mauss-Clum and Ryan (1987), writing from a nursing perspective, reported on a survey conducted among female participants (wives and mothers of adult male patients) in a family support group. Their results indicated the benefit of regular family conferences with attending clinicians in order to discuss the patient's condition and prognosis and the evaluation of future capabilities. As well, information to facilitate informed decision-making and financial counselling is also important. The situation of the primary caregiver, the wife or

mother, is highlighted in terms of the special difficulties faced by female caregivers. In particular, wives feel constrained because of the nature of the spousal relationship, while mothers feel constrained because of their difficulty disengaging from their offspring. In addition, the family is recognized to need as much help in adjusting to the injury as is the patient.

Families of head-injured adolescents and children face special problems. Hughes (1990) noted that when a child sustains a severe head injury, the entire family is thrown out of balance. Each member is faced with stressful changes in all their relationships. Stresses to the family centre on the uncertainty surrounding the outcome, the toll of long-term intensive rehabilitation, disruption of usual relational patterns, and the increased financial burden for rehabilitation services and day-to-day living costs. The plight of siblings is noted as one of the most overlooked problems facing the family. The crisis focus of the family and increased demands of the brain-injured child leave little time or energy for other children in the family. This often leads to feelings of alienation in the healthy siblings, to disruption of their normal, everyday social interactions, and to reactive acting out behaviours. Hughes pointed out that education, active involvement and participation by the family in treatment, where and when possible, facilitates understanding and provides an active outlet for caregiving that, in turn, may help maintain family cohesiveness, open communication and mutual support--all of which enhance adaptation.

Writing on the distinctive problems faced by adolescents, Blazyk (1983) highlighted the interface between normative adolescent and familial developmental issues and the recovery and rehabilitation processes. From his perspective, the accident has the potential to halt the developmental process so that the normal pull towards individuation and independence is disrupted or even reversed. Furthermore, neuropsychological consequences of severe

head trauma seriously compromise the adolescent's capacity for positive resolution of age-relevant developmental issues. Blazyk noted that families of head-injured adolescents face a variety of challenges. For example, the disruption of existing roles; a preoccupation with caring for the injured person, including decisions on care strategies and how to try to maintain some semblance of a normal family life for the benefit of other children; and marital discord as the family tries to meet increased and more complicated demands for time, energy and financial resources. Lack of significant improvement predisposes the family to increased social isolation and social withdrawal due to the patient's need for increased attention, and to the patient's often bizarre or unpredictable behaviour. The long-term rehabilitation goal centres on helping the patient and the family cope with the deficits, while also supporting the maximum degree possible of normal development. Jacobson et al. (1986) pointed out additional difficulties faced by adolescents and their families, especially regarding reintegration into the school system. This must be handled skilfully to maximize in a positive way, the student's potential to benefit.

Quantitative Studies. Beginning in the late 1970s, the Glasgow-based team of Oddy, Humphrey and Uttley initiated a long-term study of family stress resulting from head injury. The initial study (1978) focused on the subjective burden experienced by the family during the first post-injury year. A follow-up study completed two years later focused its attention on the patient's social recovery (1980). The research format included a semi-structured interview with a parent or close relative to assess the patient's social adjustment, and the patient's completion of a battery of cognitive tests and symptom checklist. Results showed that the most stressful period for the relatives occurred during the first month after the injury, and stress seemed to level off by six months, and then remained stable through the next twelve months. No significant

differences were reported between parents and spouses. The main sources of stress centred on poorly controlled behaviour due to personality changes, combined with, the sheer physical stress of caring for a disabled family member; concern for the patient's future; and fear of another accident. Twenty-five percent of the respondents said their health was affected. This was manifested in somatic or emotional complaints. The two year follow-up revealed that the patients' return to work was not a sensitive index for judging recovery. Pre-accident personality variables such as nervousness and tendency toward verbal expansiveness combined with the effects of physical injuries appeared to hinder the possibility of returning to work. At the same time, leisure activities were shown to be seriously lacking, contributing to diminished social contacts and a restricted social life. While family relationships appeared to settle down, there was an increase in difficulties with sibling relationships.

Brooks and McKinlay (1983) studied relatives' perceptions of personality and behavioural changes in patients with blunt head injuries. Their findings revealed that patient changes, as perceived by a close relative, did not always have the same implications. Duration of post-traumatic amnesia showed a weak and ambiguous relationship with personality change. The pattern of changes identified at the three months mark appeared to persist over subsequent months, especially negative changes such as reduced self-reliance and increased irritability and spontaneity. Relatives' perceptions of their subjective burden was strongly related to emotional and behavioural changes in the injured person and weakly related to physical changes. Brooks (1984) added that persisting social problems centred on diminished social contacts and a sense of social dislocation, thus causing most head-injury survivors to eventually live alone. Furthermore, complaints of tiredness, slowness, irritability,

aspontaneity, poor memory, restlessness and a sensitivity to stress were all still evident.

Recently, Moore et al. (1991), using cluster analytic techniques, investigated the relationship between family coping and marital adjustment after traumatic brain injury. Their findings indicated that family coping styles have some relationship to marital adjustment. However, their evidence had to rely on liberal statistical techniques in order to demonstrate differences among the cluster groups. Greater dyadic adjustment was reported by the wives in the high-use-of-coping-skills group, while greater sexual intimacy was reported in the low-use group. Younger families and families under substantial financial strain reported an underuse of coping skills that, in turn, had a negative effect on their marital adjustment. The authors suggested that knowledge of demographic variables at the time of the accident might be useful to identify families at risk because they underuse coping skills.

Qualitative Studies. Several researchers have initiated qualitative studies of family functioning in response to disability in order to access variables that are not amenable to quantification procedures. Cogswell's (1976) study of the family's response to disability was rooted in the grounded theory approach of Glaser and Strauss (1967) and sought to reveal the concepts that could describe what occurs in families who care for a disabled member. Unlike traditional family research at the time, this study focused on the family as a group and collected data from all family members. Families were studied in their natural habitat, the home, with an emphasis on normal living. This study presented some important methodological issues. For example, observing and interviewing the family as a group provided an opportunity to observe the nature of their group behaviour. Furthermore, separate interviews with family members shed extra light on group observations as well as on the

group interviews. Data obtained from the family measurement scales highlighted the need for a more subtle interpretation that could only be achieved by using open-ended interviewing techniques. The findings revealed that disability in one family member resulted in an alteration of priorities; a reformulation of individual and family goals; and a redefining of family composition to accommodate entry and exit of other family members as well as of adjunctive care providers and other support systems.

Karpman, Wolfe and Vargo (1986) explored complex adjustment problems and critical issues experienced by head-injured adults and their parents by using in-depth interviews that they subjected to a content analytic procedure. At the time of the study, two-to-five years post-injury, most of the head-injured participants were still very dependent on other family members for all dimensions of their lives. The dominant issues revealed by the head-injured persons included memory loss, social isolation and uncertainty about the future. Their parents were mainly concerned with the issues of overprotectiveness, financial problems and emotional strain. Common experiences reported by head-injured individuals included attempts to adapt to their new situation, an awareness of the many difficulties to be overcome, and the changes needed so that they could continue living their own lives. Parents felt a strain in many sectors of their lives as they became very involved and expended a great deal of time and energy in the recovery process.

Research data arising out of discussion groups gave Willer, Allen, Durnan & Ferry (1990) a perspective and understanding not usually present in survey research. They employed the nominal group technique (Delbecq, Van de Ven & Gustafson, 1975) that combines survey and observation techniques. This method was deemed "edifying and enjoyable for the participants" and of "immeasurable value" to the research project (p. 172). Thirteen young men with

severe brain damage, their mothers and seven siblings participated in a family retreat weekend sponsored by the Ontario Head-Injury Association. A structured, small group, discussion format was used to determine the types of problems faced and the coping strategies found most useful by the young men, their mothers and their siblings. Each group generated and rank ordered a list of family problems and a list of strategies that were helpful in coping with their problems. The results indicated that despite physical and cognitive disabilities, the young men were most concerned with problems in living. Making and keeping new friends were perceived to be most problematic, while the need to take personal responsibility for progress was identified as the primary coping strategy. They compared the commitment needed for their success in rehabilitation to the commitment required for success by able bodied adolescents in other activities such as school and sports. In addition, their problems, i.e. with peer relations, autonomy and success at school, were seen to be related to the experience of having handicaps rather than to their disabilities per se.

Mothers identified problem areas that were mostly related to the service system and its inaccessibility. They listed acceptance of their son's changes, including personality changes, as their primary coping strategy. An essential coping strategy identified was the need to become assertive with professionals and funding agencies in order to procure needed services for their sons. Siblings of these brain-injured young men listed family stress and increased worries as most problematic. They were especially concerned over their brother's quality of life and the increased responsibility they were required to assume to help out. They demonstrated significant awareness of the difficulties faced by their brothers in the everyday world, as well as a fierce loyalty and willingness to help and protect their brothers. All participants shared a common

belief in hope, determination and maintaining a good outlook on life as the most significant aspects of coping. Rehabilitation and other professional services were noticeably absent from the list of coping strategies cited. This leads one to appreciate the challenges faced by these families as they are forced to cope on their own.

Critical Evaluation of Mainstream Literature

The above-mentioned series of studies and reports attest to the plight of both head injury survivors as well as their families. The diversity of disciplines highlight the broad spectrum of physical, cognitive, emotional, psychological and social difficulties. Early research demonstrated a shared interest and concern across disciplines for the welfare and quality of life of both head-injury survivors and their families. This has been extended so that now there is a growing recognition of the interface between cognitive, psychological and social sequelae on the one hand, and family functioning, including the hardships, coping and accommodating strategies, on the other.

Empirical research literature specifically focuses on individual aspects of the head injury, and hypothesizes about the ramifications of the consequences for family members. Qualitative literature documents factors defined as both problematic and beneficial from the perspective of the head-injured person and a family member, usually the mother or spouse. Observational literature based on support groups and clinical experience provides a detailed picture of the everyday and long-term challenges faced by individual family members and the family as a whole. Yet, we still do not have a systematic study that can illuminate the essential themes and critical features, as well as the underlying family structure of family members who live with a traumatically head-injured person.

The growing recognition of the merits of including descriptive and qualitative dimensions, that address the subjective and experiential nature of being a head-injury survivor or a family member, as a complement to strictly quantitative and mainstream research, attests to the trend towards a rapprochement between research paradigms. This seems prudent in light of the complex and serious nature of traumatic head injury,

While the interest in descriptive and qualitative dimensions of traumatic head injury is actively sought in some quarters, especially the applied fields of rehabilitation and therapy intervention, many researchers still doubt the efficacy and validity of such an approach. In surveying the literature, it becomes apparent that one of the major impediments to considering qualitative research perspectives is the lack of substantive evidence of methodological, systematic and rigorous research methods that are reliable and valid. In the following sections, we will demonstrate that a descriptive phenomenological method can indeed attend to these issues in a scientific, systematic way, and can therefore be a viable and valuable complement to mainstream traumatic head-injury research.

The Transitional Position of Kurt Goldstein

Kurt Goldstein holds a critical position in our literature review of the effects of brain injury on individuals and their families. An original thinker in his own right, his theoretical contributions situate him as a significant transitional figure for our purposes. His early conceptualization (1948) of human behaviour led to the formulation of a distinctive organismic theory. His later writings (1957/1971, 1959/1971), based on clinical observation and description, show a strong affinity towards existential-phenomenological thinking and languaging. However, Goldstein remains basically within the organismic perspective in that, while he recognized the influence of the external world, he primarily focuses on

the subjective pole and treats the organism as a distinct unit separate from the rest of the world while functioning in it. The existential-phenomenological approach, by comparison, views the human person as a Being-in-the-world, with Being and World co-constituting each other. Goldstein's landmark paper, The Effect of Brain Damage on the Personality (1952), is based on his theory of human development and human existence. As such, it is a significant contribution to head-injury research and intervention.

Organismic Theory

Goldstein's organismic theory was conceptualized from investigations and observations of brain-injured soldiers injured during World War I. His observations revealed that symptoms displayed by a patient could not be understood solely as the product of a particular organic lesion or disease, but had to be considered as a manifestation of the total organism. Goldstein viewed the organism as a single unity that behaves as a unified whole rather than a series of differentiated parts. This holistic notion of organismic functioning was in direct contrast to the mind-body dualism conceived by Descartes in the 17th century and taken up and promoted by 19th century natural science psychology.

Goldstein's organismic theory includes several postulates germane to understanding human nature, and in particular, persons who have sustained a head injury. Health is indicative of the natural, normal state of the human organism. Disorganization indicates dysfunction and consequently some dimension of pathology. Preferred ways of behaving and ordering life evolve in conjunction with experience and maturation and help preserve an internal balance in the organism. For Goldstein, health signifies more than survival of the individual as a psychophysical organism. It represents not only

preservation, but more importantly, the actualization of the very nature of being human.

Self-actualization or self-realization, originally conceptualized by Goldstein, is seen as the sovereign motivating force of the organism. As a singleness of purpose, self-actualization gives direction and unity to life. The external world is seen to exert much less influence when compared to the overriding influence of the striving for self-actualization. To maximize the potential for self-actualization, the organism selects features in the environment to which it will react. When it senses it cannot control the environment, it will try to alter or adapt itself to the circumstance. From this perspective, a normal and appropriate environment provides the necessary opportunities to produce a healthy, integrated personality, while malignant environmental forces serve to prevent healthy development and may even cripple or destroy the person.

For Goldstein, the notion of concrete and abstract attitudes plays a significant role in understanding human nature, and in particular, the world of the head-injured person. The concrete attitude, bound to the immediate experience of specific objects and situations, experiences life passively. Concrete behaviour involves reacting to a stimulus in a fairly automatic or direct manner. In contrast, the abstract attitude enables humans to transcend the immediately-given aspect of sense impressions and allows them to detach themselves from these impressions, in order to consider the situation from a conceptual point of view and to react accordingly.

From a research perspective, Goldstein preferred comprehensive in-depth case studies of one person. He believed that individual case studies provide a fuller and more comprehensive picture of the integrative nature of human behaviour and personality.

Theory of Traumatic Brain Injury

Goldstein's contribution to understanding the effects of traumatic brain injury on the human personality is compelling. His theoretical concepts grew out of his work and extensive observation of young German soldiers who had suffered severe brain injuries while in combat during the First World War. His foundational premise is that personality and behaviour are interwoven and founded upon the innate pull toward self-actualization and self-realization, the prime motivating force behind all human activity. Consequently, patterns of behaviour are disclosures of the person's personality. Goldstein understood health to be a condition or order whereby the individual is able to arrange the environment in such a way that he or she is able to fulfil the demands of life. In contrast, when sick, individuals may find themselves in a state where demands cannot be met and they are unable to fulfil tasks or expectations. This may lead them to what Goldstein refers to as a "catastrophic condition" (Goldstein, 1952) because it thwarts the self-actualization process, and ultimately, existence itself.

Goldstein's most influential contribution to the study of the consequences of head injury lies in his explication of the impairments which emerge as a result of defects in concrete behaviour and in the abstract attitude. Impairment to concrete behaviour may result from the direct effect of a lesion in one cortical field, or from isolation of a field when the abstract capacity is impaired. According to Goldstein, impairment of the abstract capacity is the underlying cause of personality alterations in brain-injured persons due to its pervasiveness and ability to affect all performance fields. When viewed from the perspective of impairment of the ability to abstract, one arrives at a different understanding of the maladaptive behaviours shown by brain injured individuals.

Goldstein identifies the primary problem areas resulting from brain injury as: difficulty with memory and attention, emotional responses, pleasure and joy, sense of humour, friendship and love, and changes in language. These difficulties occur in all head-injured persons to a greater or lesser degree depending on the severity of the damage and concur with the findings of other researchers and clinicians. The above mentioned deficits lead, in turn, to reduced perceptions, thoughts and ideas; diminished or non-existent imagination and inspiration; reduced initiative and the capacity to look forward to something or to make plans and decisions; and a diminished ability to encounter others, which renders the severely brain-injured person incapable of maintaining real friendships, love or social relations. Moreover, these characteristics are consistent with impairment or loss of the abstract attitude and predispose the person to abnormally rigid, stereotyped and compulsive behaviours, bound to stimuli from within and without.

As previously mentioned, all forms of sickness have the potential to impede the natural flow of the self-actualization process. Goldstein believes that when this occurs, the human organism experiences a sense of danger to his or her existence that manifests itself in the form of anxiety. For the brain-injured person, who experiences many weaknesses and limitations, artificially structuring the environment helps maintain a sense of order which, in turn, helps protect against a sense of inadequacy. Orderliness allows the person to stick to easily-handled arrangements, and is therefore actively pursued. Likewise, busy-ness often serves as a protective measure against anything and everything that cannot be dealt with. The need for order, as a measure of control over the environment and as a protection against failure, makes the agitation and excitement that often appear when changes occur, understandable.

Goldstein believed that a patient's seemingly total unawareness of his or her defect is not simply a subjective lack of awareness. From his perspective, lack of awareness occurs when the degree of functional defect in performance is in the extreme. The patient tries to deny the experience of the functional disturbance because of a fear of the catastrophic condition that would result should the individual become aware of his or her deficits. Thus, for the severely brain-injured person, the only way to exist in an existentially-congruent manner, is to live in a prosthetic environment, that is, one specifically structured and organized by self or others so that unfulfillable tasks are minimized or avoided.

To some extent, all brain-injured individuals experience a diminished capacity for abstraction. In the extreme, the complete inability to abstract precludes the ability to imagine, to fantasize, to deliberate, and to make decisions. The individual is trapped in the concrete here and now, unable to access the realm of the future until it is directly at hand. Goldstein (1952, p. 252) gave a poignant example of a married man who enjoyed being at home with his wife and family on weekends, but who appeared indifferent and utterly estranged from his home situation when back in hospital. The reality of his situation was that, because of his impaired capacity to abstract, he could not summon up the home situation when he was not actually there.

Goldstein's holistic organismic approach to understanding personality and behavioural changes following severe brain injury throws a different light on the plight of brain-injury survivors and has significant implications for family members and rehabilitation specialists. His attention to detailed clinical observation and his profound appreciation for the holistic nature of human behaviour and experience enabled him to present a different perspective on the effect of traumatic brain damage to the human personality. His writings set the

stage for and provide a bridge between mainstream and existential-phenomenological research.

Existential-Phenomenological Approach to Tragedy and Traumatic Head Injury

Existential-phenomenological research originally focused on the experiences of individuals in their interrelationships to self, others and world and this focus is still dominant today. One could say that it grew naturally out of the early research and theorizing initiated by Husserl and Heidegger. From this perspective, relationships to others were seen to be inseparable from relationships with self and the inhabited world, and were discussed under the concept of intersubjectivity. Husserl delineated the intersubjective realm as knowable through apperception, but did not focus on it in his research. Heidegger's principle focus was on Dasein as a Being-in-the-world and all the implications that this fundamental human condition implied. Merleau-Ponty recognized the shared world of humans in a deeper and more intimate way. His notion of "embodied-subjectivity" and the primacy of human perception as the means by which humans come to know themselves and others within their lived-world, opened the way to a deeper understanding of subjective and intersubjective relationships. Alfred Schutz (1967), a renowned phenomenological sociologist, further explicated this intersubjective notion of a shared life-world and identified the unique significance of the face-to-face encounter between persons. Despite the solid foundation for exploring the intersubjective realm, phenomenological researchers have only recently started to look at family life as a viable research arena. Consequently, family-focused phenomenological research is still in a formative phase.

Contribution of Merleau-Ponty

The writings of the eminent phenomenological psychologist Merleau-Ponty are particularly relevant to this research project. His refinement of the

phenomenological method and his phenomenological analysis of Goldstein and Gelb's celebrated case study of their head-injured patient Schneider (Merleau-Ponty, 1965/1942), demonstrate the efficacy of a phenomenological research method to further our understanding of the experience of living with a head-injured person. While Goldstein and Gelb provide a wonderfully detailed description of Schneider, who sustained a penetrating missile wound to the occipital region of the cortex, it is Merleau-Ponty who revealed the different existence experienced by Schneider and other persons with similar head injuries.

Merleau-Ponty originally intended to use the case study of Schneider to help illustrate the limitations of both empiricist and intellectualist linear interpretations of pathology, and to highlight the nature of normal functioning by contrasting it to pathological functioning. The end result, however, led to a more comprehensive understanding of the underlying disruptions to the uniquely human dimensions of existence, especially intentionality and embodied-subjectivity.

Merleau-Ponty's early writings, as mentioned in Chapter II, identified three orders of being, i.e. the physical, vital (living) and human orders (1965/1942). The distinguishing feature of the human order is that the person, as an intentional embodied subject, has the capacity for transcendence and for creativity. It is within the human order that the gravity of brain injury takes its toll. From the writings of Goldstein, we learned that brain trauma affects the individual's abstract attitude which has far reaching effects. From Merleau-Ponty's phenomenological analysis, we learn that impairment of the abstract attitude directly affects intentionality and the person's sense of being as an embodied-subject-in-the-world. In everyday terms, the brain-injured person's ability to be conscious of something or to be directed toward something

(intentionality), and to be able to engage fully with the world (embodied-subjectivity) are diminished. This, in turn, leads to the different sense of existence and altered intersubjective functioning.

The scientific literature on the case study of Schneider describes his difficulties in performing abstract movements as a result of his disordered visual sense, i.e. his psychological blindness resulting from the occipital brain injury. However, from the perspective of Merleau-Ponty (1962/1945), the effects of the original neural disconnection is seen to go beyond the person's perceptual field. He posits that the "intentional arc", by which the senses, intelligence, sensibility and motility are integrated, is affected. What we see is a separation or limited capacity for the integration of perceptions. The impairment to the intentional arc, in turn, affects the general organizational structure of human behaviour along with the orientational structure. From a phenomenological perspective, the multiplicity of impairments demonstrated by Schneider in performing abstract movements are seen to be interrelated to his inability to project himself into possible or imaginary situations, as distinct from actual ones. He lacks the natural power of projection normally seen in healthy persons and because of this, he is "tied to actuality and lacks liberty" (1962, p. 135). His pathology forces him to rely on conscious thought as a means of enabling him to perform movements that healthy individuals are habitually able to perform.

From a phenomenological perspective, it appears that the source of the disruption to intersubjective functioning arises out of the disruption at the foundational level of embodied subjectivity. This manifests itself in altered perceptions and sense of self, as well as in an altered ability to interrelate with others and the outside world. When temporality and spatiality are altered or distorted following brain injury, one's sense of constancy and continuity are also

altered. In turn, personal existence and the sense of being, along with one's sense of personal identity are changed. The head-injured person's body is no longer a reliable subjective source of reference. Furthermore, language no longer provides a means to authentically encounter the world nor to establish a full relationship with others. Thus awareness of others, as living human beings in a shared world, and the experience of the world as a dynamic co-constitutive entity, is sorely compromised. In essence, former, familiar ways of relating to self and others are no longer viable. Until new ways come into being, either through new learning or through external, prosthetic sources, the head-injured person will continue to experience a different and strange existence.

Merleau-Ponty's phenomenological understanding of Schneider's plight provides a window on the altered life-world of people suffering the consequences of brain injury. For many, life post-injury is at first experienced as foreign and unfamiliar. There is a tangible element of strangeness interwoven with memories of familiarity. Family members are also thrown into a strange and unfamiliar experience. Not only must they deal with the initial shock of the accident, they may also have to contend with the reality of physical difficulties as well as with the strange and unfamiliar behaviour and disposition of their loved one. Suddenly they are faced with ambiguity on a daily basis. The rules of appropriateness and expectation have changed and, for a time, are unpredictable. An understanding of the underlying changes to the structure of Being of the head-injured person could help family members and professionals provide the necessary prosthetic and supportive environment.

The Phenomenology of Tragedy

The phenomenon of tragedy has not yet been considered as a specific constituent of head-injury research, despite the observation of the despair and anguish experienced by many survivors and their families. This may be partly

due to traditional natural scientific approaches, which focus on the causal relationship between the event and the survivor's symptomatic reaction and coping strategies, and which give little attention to the survivor's own interpretations of the meaning of the event. Within the head-injury literature, there are repeated calls for case study investigations that might capture the subjective realm. So far, however, the method of choice remains predominantly a natural scientific one, that is, one focused on identifying the specific effects caused by the head injury, on answering why the subjective symptoms emerged, and on how the survivor and the survivor's family adapts to the traumatic experience. In effect, the impact of the head injury is reduced to discrete behavioural, physical, emotional and cognitive responses to the injury. In contrast, an existential-phenomenological approach aims to describe the lived experience in terms of its meaning and its existential significance for the survivor and the family.

Lifton's (1979) definitive research into survivor experiences and his formulation of a traumatic syndrome provide a starting point for investigating the relevance of tragedy to the phenomenon of head injury. His writings may be considered within the existential tradition since he uses subjects' descriptions of their experiences and he strongly emphasizes the importance of issues related to death. For Lifton, survivors are people who have "come into contact with death in some bodily or psychic fashion and have remained alive" (p. 169). Lifton proposes a traumatic syndrome consisting of five interrelated themes, each of which presents a facet of death or death-images, and are laden with significance to the person. These interrelated themes within the traumatic syndrome are: death imprint, death guilt, psychic numbing, conflicts around nurturing and contagion, and difficulties with meaning-attribution.

Lifton believes that the survivor must find meaning and significance in the traumatic event in order to be able to integrate and transcend the trauma. This necessitates confronting the traumatic event(s) and the associated guilt and numbing, reordering life to integrate the traumatic event, and finally renewing one's self in order to begin again the forward journey of one's life. The struggle to find meaning entails a process of reformulation which moves the person towards a new sense of self, accompanied by an inner structure that is able to accommodate the traumatic event. Establishing a lifeline on a new basis, including both proximate and ultimate involvements, is integral to the process of integration and transcendence.

Carrere's (1986, 1989) phenomenological research into the realm of tragedy is a landmark contribution to the field of phenomenological research and is directly relevant to the proposed research project. Drawing upon previous natural scientific research, Carrere notes that tragedy is traditionally viewed as an anomaly of ordinary life and, as such, the common observation of defensive denial is understandable. However, from a phenomenological viewpoint, this spectator level perspective is deficient because it perpetuates a psychological separateness between the person and the emotionally difficult experience. Carrere states that defensive denial misses the psychological reality. The person does experience something, but it is opaque to the observer. Thus, tragedy conceived as an event with its relevant sequelae, is insufficient to fully explain the experience of tragedy.

In order to articulate the experiential mode of tragedy, Carrere chose a phenomenological method that uses written protocols, elaborated upon during open-ended follow-up interviews, as the primary research data. Eight participants described in detail, and in their own terms, the experiences they considered tragic, i.e. death of a twin, death of a brother, adoption, surviving a

pogrom. As well, participants were asked to describe how they experienced the research process itself. This was then added to the data pool.

The research findings indicate that the structure of tragedy includes the following interrelated themes: a prologue or pre-tragic order that includes a pre-tragic innocence; a tragic rupture or displacement whereby the spatial and temporal dimensions of psychological life are compromised and constricted on sensorial, social and existential levels; a tragic return involving an expansion of personal influence through self-education, and transcendence of the tragic displacement through mastery over incongruity, inadequacy and isolation; and finally, a re-ordering and return to the social world that includes a new version of self and world and one's place in it.

The pre-tragic ordering of life sees the person "nested within a web of relations" (p. 108) within the everyday social world. These relations provide a sense of certainty, a sense of being and belonging. Restrictions on personal agency do exist, but are experienced as meaningful definitions or boundaries of psychological life versus the experience of limitations and impositions of the later tragic order. Change is experienced on an ongoing basis as the varying continuity of things, and life in general is experienced as personal, intimate and mine.

The advent of a tragic happening throws the person into a radically foreign realm that challenges personal integrity and the common sense of things. Carrere (1989) writes, "In tragedy, the individual is tragically isolated, homeless and no longer nested in a web of relations" (p.120). Recovery from tragedy is seen as a return to a social world and to a sense of belonging. A new sense of home and a new configuration of personal significance with self and with others must be created. The meaning of tragedy must be integrated

into the new configuration. This necessitates transcendence of pre-tragic innocence as well as transcendence of tragic displacement.

The phenomenon of traumatic brain injury is a tragedy. The rupture and severing of neural fibres seems to lead to a disruption of the individual's psychological existence and a related disruption of family and social existence. Because traditional research into brain injury sequelae and family functioning following brain injury has remained primarily at a causal, linear level, it has fallen short of a fuller and deeper appreciation of the disruptive aspects of brain injury to the existential realm of the person and his or her family. Only when we are able to tap the deeper experiential dimensions of the phenomenon will we be able to fully understand its extensive impact.

Phenomenological Study of the Experience of Traumatic Brain Injury.

Liberto (1990) recently completed a doctoral dissertation using a phenomenological method that explores the experiential realm of the traumatically brain-injured person within a social context. Unlike natural scientific studies which seek to describe in detail the behavioural, cognitive and/or emotional consequences of traumatic brain injury, this study endeavours to present an integrated perspective of brain injury sequelae as they interact in the social realm of the survivor. The research participants included five traumatically brain-injured persons between the ages of 15 and 35 who had participated in an inpatient or outpatient interdisciplinary rehabilitation program, and a selected normal partner. The partners were parents, siblings and a community skills counsellor. Each brain-injured participant was asked to describe a specific interpersonal interaction that had occurred within the previous month that he or she judged to have been difficult or problematic. The designated partner was asked to describe the same problematic interaction during a separate interview. A semi-structured

interview format (Kvale, 1983), focusing on the brain-injured person's life-world, was used. All interviews were video-taped, transcribed and analyzed according to the phenomenological method formulated by Giorgi (1985).

Phenomenological analyses of the interactions described by the brain-injured participants reveal a life-world that is limited to the immediate and concrete. The poor insight into deficit areas protects the person's sense of wholeness and competency. Relationships with a significant other provide external structuring and facilitate daily actions and choices, but they tend to remain centred on the brain-injured person. More specifically, the protocols of the brain-injured participants disclose an inability to imagine or comprehend alternative perspectives or to process two or more conflicting ideas simultaneously (which is consistent with cognitive inflexibility and concreteness). Furthermore, these brain-injured people seem to have a sense of their defectiveness with regard to their daily functioning, but it does not manifest itself in their conscious awareness. As a result, they tend to underestimate their limitations and overestimate actual performance while continuing to feel a sense of being defective or different from their former selves and from others. Perceived lack of control over feelings and behaviours connected to these feelings appears to arise from the muted ability to mediate between emotional reactions and behaviours. Interpersonal relationships tend to be skewed in the direction of self-focus. The injured person depends on others to provide the external structure to compensate for his or her defective internal structuring. Most importantly, these injured participants employ strategies in order to maintain a world that is felt to be safe, that is, one that helps preserve a sense of an intact self and is able to defend against their own sense of chaos.

Normal participants, on the other hand, describe efforts to facilitate normal functioning in their brain-injured partners, where and when possible, by providing the necessary external structuring. The role of protector against negative or difficult situations for the injured person emerges as the most significant factor in the descriptions. Interestingly, the normal partners appear unaware of the extreme emotional experiences of the injured person. Instead, they describe feelings of inadequacy when faced with the brain-injured person's problem-solving and reasoning difficulties and this is exacerbated by difficulties in knowing whether the injured person comprehends their concerns. In addition, normal participants give evidence of a strong tendency to identify with the injured person's feelings and perspective. However, because the injured person seems oblivious to this perception, the normal participant is denied any sense of validation or verification.

A comparison of the situated structures revealed that both partners (brain-injured and normal participants) were unaware of the reciprocal roles played by each other, especially in terms of the "dysfunctional communication loop" (Liberto, 1990, p.84). This loop manifests itself as ineffective, repetitive and inhibitive of extrication by positive means. At a fundamental level, the normal partner acts as a giver and protector of external structures for the brain-injured partner, to help this person compensate for the diminished or lost capacity for internal structuring. This prosthetic structuring helps the brain-injured partner to maintain a modicum of appropriate behaviour in everyday living. At times, when the brain-injured person "gets out of control" and exhibits extreme emotional reactions and frustration along with a deterioration in cognitive processing, realignment efforts by the normal partner tend to have limited effects for both persons. Because neither experience the other as comprehending their point of view, meaningful communication breaks down

and leads to a further sense of isolation for the brain-injured person. The implications of this dysfunctional communication loop is seen to be the crux of many difficulties and frustrations experienced by caregivers and service providers alike when interacting with brain-injured persons. At the same time, Liberto's explicitation of the fundamental dynamic of this interactional pattern may provide an alternative perspective for intervention strategies.

Many of the dysfunctional issues presented in Liberto's study, including difficulties with interpersonal communication, echo results of other reports (e.g. Goldstein, 1952; Lezak, 1976, 1986). However, the explicitation of how these deficits and difficulties are interrelated and played out in the social context of the brain-injured person distinguishes this phenomenological study from previous research.

In our everyday world, where perfection and excellence are idealized, a sense of incompetence or even the fear of incompetence is easily elicited in brain-injured persons. This fear of finding oneself in a compromising position often precipitates emotional reactions that are not easily subdued or controlled by the brain-injured person. The inability to entertain alternative and multiple perspectives and solutions constricts the brain-injured person's world and life space. His or her focus of attention becomes more and more circumscribed until the major focus becomes the self. This is labelled egocentric behaviour by mainstream researchers and clinicians. In its extreme, the ability to comprehend the perspectives of others is sorely impaired and this, in turn, directly affects interpersonal relationships. From a more comprehensive phenomenological approach, Liberto redefines this egocentric phenomenon as a "deficit egocentrism" (p.80). This is in contrast to the label of "personality change" or "libidinal regression" formulated in traditional brain-injury literature. She sees it as a part of the cognitive affective sequelae of traumatic brain

injury, i.e. a logical consequence of cognitive infirmities and also of the constricted world the individual builds to maintain a zone of competency. Liberto's understanding of "deficit egocentrism" echoes Goldstein's (1952) writings on the loss of "abstract attitude" that also restricts the brain-injured person to a world of immediate experience and renders the person helpless when faced with an "other than concrete" experience.

Knowledge and awareness of the interface of cognitive impairments with social and behavioural difficulties could provide the foundation for helping caregivers and service providers create prosthetic environments that would allow brain-injured persons to function with a sense of competency. Liberto suggests that by helping the family create an environment conducive to the maintenance of a tolerable level of competency for the brain-injured person, certain aspects of denial and defensive strategies may decrease because the anxiety level would also be reduced.

Phenomenological Theory and Research on Family Life

Early existential and phenomenological investigations into family living explicate the intrinsic relevance of the existential categories of time and space to family life as well as to individual experience. Curry (1967) proposed the phenomenological method as an effective means to directly analyze the structures of family life and to describe the interdependent nature of family roles, affect and process to family living. Kaye (1986) added that an existential-phenomenological approach to family therapy could help to integrate existential and systemic considerations into the theory and practice of family therapy. For example, existential anxiety is identified as a core issue within family life that has a tendency to emerge at transitional or nodal moments, especially when family integration is threatened or when personal individuation or individuality is thwarted. Additionally, existential anxiety is seen to have the power to distort

the construction of reality, to influence family interaction patterns, and to have the potential to disconfirm individual family members. Kaye cautioned against "structuralist blinkers" and urged us to bear in mind the unique human characteristics of living family systems in contrast to abstract structural or strategic principles.

The primary contributors to the development of an existential-phenomenological research method for exploring family experience are Laing and Esterson (1970) and more recently Mook (1985, 1986a, 1987, 1989). Laing was the first major investigator to study the family unit as a whole and from a singularly phenomenological perspective. Diverging from their mainstream science colleagues, Laing and Esterson (1970) explored the familial life-world of persons suffering from schizophrenia. They provided a rationale for a social-phenomenological method based on Sartre's existential-phenomenology, with its concepts of praxis, process and intelligibility. As well, they formulated a phenomenological research project aimed at revealing, from the perspective of each family member, what sort of world the family had fleshed out for itself. Most importantly they demonstrated a method capable of revealing inter-perceptions, inter-actions and inter-experiences within the family as a whole. The notion of family nexus referring to the multiplicity of inter-relationships between family members, was seen to be the central organizing feature of family life and was characterized by "the enduring and intensive face-to-face, reciprocal influence it exerted on each members' experience and behaviour" (p. 21).

Laing and his co-researcher Esterson's contribution to family research methodology is significant and enduring. At the time, their attention to the family constellation was a definite step in a more positive direction, away from a singular focus on the identified patient, and away from blaming the

schizophrenogenic mother. Despite Laing and Esterson's pioneering contributions to phenomenological family research, their studies centred mainly on individual, dyadic and triadic perspectives within the family, with some neglect of the family system as a whole.

Contemporary research into family functioning has witnessed a steady pull towards the acceptance of a systemic paradigm as the theoretical model of choice. This trend toward a more inclusive and contextual perspective views the family as a hierarchically-organized system, whose members form its parts and interrelated subsystems. Mook (1985), however, suggests that even the systemic approach has limitations and drawbacks because it too follows the dictates of the natural scientific approach with its emphasis on the primacy of the system as an innate force able to structure and organize family life. In response, she proposes a phenomenological human science approach as a complementary alternative to both the understanding of a variety of family life phenomena and the practice of family therapy. Her early writings focus on a critique of systemic and structuralist perspectives which are for the most part accepted as the most comprehensive and advanced theoretical orientations to the understanding of family living. Her discussion of the concept of family structure discloses the foundational nature of this concept to both the systemic structural perspective and the phenomenological approach. She also brings to our attention the fundamental differences. The systemic approach, with its adherence to the natural science paradigm, views structure as "a formal entity that provides explanatory principles for the cybernetic and regulatory features of closed and open systems" (1987). In contrast, structure, conceptualized from a phenomenological perspective, is characterized as the complex totality of relationships between the parts within the whole. She deepens the discussion with her application of Merleau-Ponty's philosophical concepts to the study of

family life and family therapy. With reference to Merleau-Ponty, she states that human structures, as compared to physical and vital structures (Merleau-Ponty, 1965/1942), signify the unique ability of human beings to transform situations as well as their own selves. This existential capacity for transcendence opens up the realm of the possible, and in fact, compels the human organism to move beyond created structures in order to create new ones. Thus the normal family, from this perspective, is understood to have the capacity to create, transform and transcend its own structures. Furthermore, it is also seen to have the capacity to create and recreate, when necessary, structures unique to their own lives.

According to Mook, phenomenological family research endeavours to reveal the nature of the family structure sustaining and maintaining the phenomenon under investigation. While surface structures disclose the explicit nature of the phenomenon, it is the structure's deeper dimensions which harbour the implicit personal and interpersonal meanings within the family relationship. She asserts that the concept of the We-relationship, originally conceptualized by the phenomenological sociologist Schutz, is critical to understanding the distinctive shared world of the family, as well as the avenue by which the researcher may enter the family's world. Additionally, phenomenological family research is able to shed light on phenomenological concepts such as embodied-subjectivity, intentionality and meaning creation as they reside within the family constellation.

Mook's recent work is moving in the direction of exploring other foundational theoretical concepts relevant to both family life and family therapy, i.e. the realm of intersubjectivity and the relevance of narrative structures (1989). This direction proposes a new theoretical basis for family therapy that is grounded in a phenomenological-hermeneutic approach. Her interest in the

concept of intersubjectivity, for example, presents a significant shift away from traditional family research where the primary focus rests on the fundamentally mechanistic notion of systems. Instead, she posits and demonstrates that from a phenomenological point of view, "the family is co-constituted as an intersubjective community" (p. 15). Thus, family members are not simply subordinate parts of a system, they are subjects in their own right. They relate intentionally to other family members so that each member is a self which interrelates with and forms an integral part of the family community. Moreover, she suggests an interwovenness between family dialogue (i.e. narrative structures) and the structural configuration of a particular family's life. From her perspective, structural configurations of family life and the expressed narrative structures of individual family members are co-determinant, with the power to co-create and transform each other. Thus, Mook's investigative work, grounded in a phenomenological-hermeneutic approach, into the interrelationship between narrative structures and intersubjectivity (1989) predates recent family therapy literature promoting the primacy of narrative in family therapy (Epston, 1994; O'Hanlon, 1994; Wylie, 1994).

Mook's contributions, especially regarding the power of phenomenological research methods to elucidate the implicit, deeper structural constituents of family life, highlight the unique applicability of phenomenological theory and praxis to family research. They will be shown to have a direct bearing on the proposed study of family members' experiences of living with a head-injured person.

The existential-phenomenological perspective of family life, tragedy and the plight of brain-injured persons goes beyond a mere recounting of contributing factors and symptoms. From this perspective, we gain a richer,

deeper understanding of the experience of being brain-injured and of interacting with a brain-injured person.

Regarding the present study, the writings of Goldstein, Merleau-Ponty, Carrere, Liberto and Mook figure prominently within the presented literature review. Both Goldstein and Liberto emphasize the constricted life-world of brain-injured persons resulting from their impaired abstract reasoning and their reduced ability to entertain alternative and multiple perspectives which, in turn, decrease their awareness of the external, outside world. Consequently, the life-world centres on the immediate, the concrete and the self. The life-world is further restricted by the vital need to preserve a sense of existential wholeness and integrity, which is actively pursued in order to maintain a sense of competency in the face of deficits and sense of defectiveness. Goldstein refers to an "impaired intentionality", that special gift we humans possess that is so necessary to our sense of self and to our ability to effectively interact with others and our world. Liberto alludes to this fact in her descriptions of the brain-injured person's endeavours, albeit outside of consciousness, to preserve a sense of intactness and a sense of competency through preferred behaviours.

While both Goldstein and Liberto address the impaired intentional realm, they do so at an intermediate level and fall short of addressing the essential meaning and, therefore, the broader significance of this disruption or slackening of the intentional capacity. They also miss the crucial connection of a concomitant impairment to the human order described by Merleau-Ponty. It is here that we get a glimpse of the real tragedy of traumatic brain injury. When the brain is injured, the abstract attitude is impaired which, in turn, impacts on the person's intentional abilities. Consequently, the person is relegated, to a greater or lesser extent, to living and experiencing life at the "vital" level

described by Merleau-Ponty (1965/1942). Goldstein and Liberto show that while intentionality is disrupted or distorted, it nevertheless continues to exist and function at a deeper level in terms of preservation of personal integrity and protection against situations that have the power to highlight impairments and differentness. This level of intentionality was defined as "operative intentionality" by Merleau-Ponty (1962/1945, p. xviii).

With regard to families living with a traumatically head-injured person, we may begin to appreciate the depth and breadth of their plight when we begin to sense and understand the impaired intentional capacity and its interrelated effect on human functioning. Interwoven with the consequences of acquired head-injury is the phenomenon of tragedy that was eloquently described by Carrere. Many head-injured persons and their families are living examples of a temporal unfolding of the tragic experience, of an existential constriction of the temporal, spatial and interpersonal dimensions, and of the need to restructure and redefine one's personal and family life by integrating the tragic event and its sequelae. It is proposed that in using an existential-phenomenological approach to the study of family members' experiences of living with a head-injured person, we may phenomenologically tap into this experience in order to reveal the existential features of the disruption to personal and family life.

Chapter IV

METHODOLOGY

Personal horizons of meaning are always present in life. They are no less present when we conduct research. Drawing on my academic training in existential-phenomenological psychology, my interest in how families deal with traumatic events and my own personal experience of living with a traumatically head-injured daughter, I decided to investigate how the occurrence of traumatic head injury affects family life.

While my own experience with this phenomenon requires the "bracketing" or putting aside of related experiences and knowledge when listening to the descriptions presented by others, it also provides me with a heightened sensitivity (i.e. openness and receptivity) to the plight of those who valiantly struggle to overcome the after-effects of traumatic head injury, as well as those who live with head-injury survivors. From this starting point, it is hoped that the results generated by this investigation will offer a deeper understanding of the interrelated existential-phenomenological themes which constitute one family's life-world following traumatic head injury.

In this chapter we present an overview of the phenomenological method as it pertains to family life, the basic characteristics of phenomenological research and then phenomenological method used for this study.

Development of the Phenomenological Research Method as it Pertains to Family Life

The phenomenological method, first proposed by Husserl, resides firmly within the human science research tradition and provides a systematic and rigorous alternative to mainstream psychological research methods based on the natural sciences. While Husserl's earlier phenomenology was situated within a transcendental philosophy, his later theoretical writings acknowledge

the importance of the life-world, the living body and intersubjectivity within the experiential realm of human persons. These broader phenomenological insights heighten the relevance of Husserl's writings for present day psychologically based phenomenological investigations.

The phenomenological method formulated by Husserl requires a distinctive reflective reduction so that the natural attitude (i.e. the attunement to everyday life) may be transformed into that of the phenomenological attitude. While in the stance of the phenomenological attitude, the researcher "brackets" (i.e. sets aside) theoretical preconceptions and prejudgements and through an active process of reflection and imaginative variation, the essential and invariant structure of the phenomenon is uncovered.

Inspired by Husserl's later writings, especially on the the foundational nature of the life-world and the living-body as "the sole absolute point of reference" (Bell, 1990, p.222) in the surrounding world, Merleau-Ponty (1962/1945, 1965/1942,) extended Husserl's original phenomenological approach to include the existential dimensions identified and formulated in Heidegger's analysis of Being-in-the-world. Concurrently, Merleau-Ponty's critical phenomenological investigations into the limitations of contemporary psychological research led to a formulation of a phenomenology of perception and of the lived-body as the ground and inherent link between the individual and the life-world. In applying his existential-phenomenological method, he demonstrated the efficacy of scientific investigation into the phenomena of lived-experience of a subject who exists in a shared world with others over time.

More recently, Giorgi (1970, 1975, 1985) systematized the methodologies of both Husserl and Merleau-Ponty into a phenomenological-psychological method of analysis. While several variations of this method are presently in existence, (e.g. Fischer, 1974; Halling & Leiffer, 1991; von

Eckartsberg,1986), the one used for this particular study is based primarily on the method of Giorgi (1985). Briefly, this phenomenological method utilizes descriptions of phenomena of lived experiences from naïve subjects and sometimes from researchers to furnish the raw research data. The descriptions are then subjected to a phenomenological reduction and analysis wherein the common assumptions, theories and past knowledge of the everyday world are "bracketed" or held in abeyance, thus permitting the phenomenological attitude to prevail. Through an active process of reflection and imaginative variation, the explicit and implicit meanings of the phenomenon are unveiled. An invariant, general structure is thereby revealed.

Drawing upon the pioneering work of Laing and Esterson (1970), the theoretical writings of Schutz (1967) and the methodological writings of Giorgi (1985), Mook (1985, 1986a, 1987) has adapted the phenomenological method to the study of the family unit as a whole. Laing and Esterson were the first researchers to study families utilizing a distinctly phenomenological research method. The focus of their investigations centred on the nature of familial inter-perceptions, inter-experiences and inter-behaviours. Their ground-breaking research provides a starting-point for all phenomenological family research. Mook's (1986b) theoretical investigations further the advances made by Laing and Esterson when she suggests that the face-to-face We-relationship explicated by Schutz provides the theoretical foundation for exploring and understanding the subjective and intersubjective inter-actions and inter-experiences of family members along with their intended meanings. She posits that only in the context of the face-to-face We-relationship is it possible for the researcher to be attuned to the immediately lived family experiences as they occur. Only in a face-to-face relationship is it possible to directly witness how family members mutually and reciprocally perceive and influence each other,

and to also arrive at a sense of the potential meanings of family members' verbal and non-verbal behaviours.

Furthermore, phenomenological family research acknowledges the reciprocal and inherent dialogal nature of the research process. Just as the co-participation of all family members is considered essential to the research process, the personal involvement of the researcher within the research process is also seen to be inseparable. The researcher's role as participant-observer requires the researcher to be actively attuned to the lived experiences of family members, and also able to bracket theoretical and professional knowledge and prejudgements.

The proposed research project aims to integrate Giorgi's phenomenological research method and the adaptations formulated by Mook for the purpose of investigating the phenomenon of head injury as it pertains to the whole family constellation. It is anticipated that an existential-phenomenological approach will be able to plumb the depths of the family's lived experience in order to reveal the existential significance of what it is like to live with a head-injured person.

Basic Characteristics of Phenomenological Research

The answers we derive from research are largely determined by the questions we ask and the way we ask them. Thus, when we seek to investigate the meanings of lived experience, it is critical to utilize a research method capable of addressing and capturing the intrinsic nature of the phenomenon we are researching. For our study, a human science approach and the phenomenological method in particular became the method of choice for an exploration into understanding the perceptions and experiences of family members who live with a traumatically head-injured person.

Phenomenological research is situated within the human science tradition. In accord with traditional mainstream natural scientific methods, it strives to be systematic, methodical and rigorous. While both natural and human scientific approaches seek the same research goal, i.e. the search for knowledge, they do so by different methods. Because phenomenological research arises from a paradigm rooted in the human science tradition, basic research criteria determined as critical to rigorous natural science methods, are conceived and formulated in ways that reflect its different paradigmatic stance. Thus, criteria arising from a phenomenological research approach address issues such as discovery-orientation, fidelity to the phenomenon, consistency across research procedures, and the inseparability of subjective and objective dimensions of human experience, while natural science criteria focus on causality, validity, reliability, objectivity and generalizability.

Phenomenological research is discovery-oriented and proceeds from a stance of openness to what the phenomenon is, i.e. how it manifests itself, what is the nature of the implicit structure underlying the phenomenon. As a discovery-oriented process, phenomenological research does not originate from a set of research assumptions that form the ground for hypothesis formation and experimentation as employed by natural science methods. Rather, it seeks to uncover and make explicit the implicit meaning structure of the lived-nature of the phenomenon under investigation, including new aspects which were not previously discernable or discriminated (Giorgi, 1988). Thus, from a phenomenological perspective, the notion of causality in its linear or additive form is viewed as inadequate in its ability to address the full complexity of the phenomena of lived experience. Instead, descriptions emerging from reflection and disciplined analysis replace experiment, and descriptions of the

matrix of interconnected constituents replace cause and effect relationships (Valle, King & Halling, 1989).

From a human science perspective, the concepts of validity and reliability are approached and appreciated differently than from within a natural science perspective. Writers such as Salner (1986) view traditional natural science definitions as too narrow to do justice to the breadth and depth of human science research which investigate phenomena of human living. From a phenomenological approach, Giorgi (1985) views the question of validity in terms of the need for fidelity or faithfulness of the research results to the phenomenon under investigation, in contrast to the call for accuracy or confidence in the measuring instruments demanded by natural science research (Polkinghorne, 1989). More specifically, Giorgi (1988) posits that a phenomenological research approach must "adequately describe the general essence that is given to the consciousness of the researcher" (p.173), i.e. that which is invariant about the phenomenon. Wertz (1984) and Herron (1988) further suggest that cohesiveness and coherence figure strongly in determining the phenomenological validity of research results. For Wertz, the question asked is whether the structure is internally cohesive, i.e. does it include all meaning constituents of the phenomenon expressed implicitly and explicitly in the original description, while Herron asks whether the research conclusions are coherent with each other, that is, whether they are consistent, interdependent and mutually illuminating. Furthermore, it is critically important that the phenomenological description of the general structure provides an accurate portrait of the common features and structural connections (Polkinghorne, 1989) that are implicit in the written protocols.

Consistency corresponds to the natural science criteria of reliability. Within a phenomenological approach, researchers aim for consistency across

research procedures, i.e. between the description of the invariant structure revealed by the phenomenological reduction and the phenomenon as it is described by the research participants (Giorgi, 1988). Specifically, consistency means retaining a strong and oriented relation to the phenomenon under investigation while also moving toward a sense of the whole, without losing sight of or neglecting details and nuances. As well, consistency in phenomenological research demands accurate descriptions of the phenomenological structure, the research process and the presence of the researcher as a participant-observer within the process, in other words, across all facets of the research investigation.

From a human science perspective, scientific objectivity, that is the pursuit of a pure object uncontaminated by subjectivity, is understood to be both unrealistic and a denial of the intrinsic unity of subjective and objective dimensions of lived-experience where mind and body are interwoven as embodied-subjectivity, and behaviour and experience share an interrelatedness. Most importantly, person and world are understood to be co-constituted as Being-in-the-World with intentionality providing their underlying interconnectedness. If we isolate human behaviour from experience and study only that which is external and observable, according to natural science principles, then we risk overlooking the significance of the meaning of experience as well as of behaviour. In contrast, a human science approach honours and seeks to disclose the intrinsic interrelatedness and co-constitutionality of behaviour and experience by uncovering their intentionality. It also recognizes that the meaning of human action is interdependent and inseparable from the world in which it occurs. In this way, a phenomenological approach, in seeking to be truthful to the fullness of human experience, is seen to be ultimately more responsive to the lived-dimension of human existence.

The general structure that is disclosed by a phenomenological analysis of the phenomenon, as experienced by several subjects, aims to reveal the foundational nature of the phenomenon. For this reason, it has the power to go beyond the natural science criteria of generalizability. Because the general structure is attentive to the inseparability of the subjective and objective dimensions of human existence, it reveals the implicit meaning structure underlying the phenomenon under investigation including the meaning of the configurations of lived-experience embedded within the phenomenon. Thus, phenomenological research finds itself in a stronger position to make suggestions for change and fulfils the human science criteria of usefulness and practicality.

Within a phenomenological research approach, the natural scientific notion of researcher bias is conceived and appreciated differently. Rather than attempting to control or even exclude the researcher as a participant in the formal research process, phenomenological research recognizes and honours the researcher as an active participant, a co-contributor within the research process. Researcher and participant(s) are both considered to be meaningfully present in the research situation, but in divergent ways that must be thoroughly explicated (Giorgi, 1985). Within the data gathering phase as well as within the analytical phase, researchers carry full responsibility to be aware of their presence and power to influence the research process. With this awareness, they must be able to "bracket" and temporarily set aside theoretical knowledge and assumptions in order to be open to the phenomenon as it is revealed by the research participants. As a participant-observer, the researcher must also reside in a stance of openness and responsiveness to participants and the phenomenon that is being revealed.

Phenomenological Research Method for This Study

Justification

For this study, a phenomenological method was chosen as the most appropriate means to bring to light the nature of what it is like to live with a head-injured person. We endeavoured to reveal and clarify the alterations to the family constellation and familial life, especially in terms of how this tragic disruption affected the most fundamental dimensions of being, namely the intersubjective realm of relatedness to self and others. Furthermore, we sought to uncover the implicit structural meaning constituents forming the underlying matrix of the phenomenon of living with a head-injured person as experienced by our research participants.

Phenomenological research studies phenomena of human existence. Since it looks to the life-world as the ground from which all experience arises, it begins with naïve individual descriptions of everyday experiences illustrating the phenomenon being studied. Thus, we asked our research subjects to describe in detail how their family member's head injury had affected their personal and family lives. To broaden the scope of our research project and to remain faithful to our research focus of exploring the experience of the family, we also included two family interviews involving all family members. The phenomenological analysis of the written protocols and verbatim transcripts of the family interviews was a systematic endeavour to reveal the psychologically meaningful themes and structural configurations of the phenomenon as experienced by our research families.

We now present a description of our research process, including how participants were recruited and selected, brief descriptions of the research families, the actual research process and the data analysis.

Recruitment and Selection of Participants

Following pilot work, criteria for the selection of research participants were determined. The original criteria for subject selection centred on intact family constellations to include two parents and at least two siblings living in the family home, with a head-injury survivor capable of responding either in writing or orally to the written research questions and able to participate, at least minimally, in the family interviews. The time frame following hospital discharge was specified to be from six months to two years to ensure that the family had sufficient opportunity to fully experience the effects of living with a head-injured person.

Initial participant recruitment was through the local head-injury association newsletter. When this avenue proved fruitless, the director of physical medicine at the local medical facility providing intensive inpatient and outpatient rehabilitation services for head-injured persons was contacted and provided with verbal and written information about the project. She recommended and contacted several families to explain the researcher's request. Those families showing interest were referred to the researcher who then made the initial research contact by telephone. Through this referral source, two relatively similar families were recruited, and the research process, described in a following section, was initiated.

Description of research families.

Family "A" consisted of middle aged parents with two young adult sons aged 23 and 19 years respectively. Approximately 18 months previous, the eldest son had sustained a severe traumatic head injury. He had been a passenger in an automobile where the driver failed to negotiate a stop sign at an intersection with a major highway in Eastern Ontario and the automobile was hit by a transport truck. Following emergency attention at the local hospital, he

was air-lifted to a major trauma hospital. Approximately four months later, when medically stable, he was discharged and taken home at the request of his parents. His condition at that time was described as being in a "persistent vegetative state" due to severe brain injury and his comatose state which lightened only intermittently. At the time of the accident both parents were fully employed and the injured son was employed part-time having recently completed one year in mechanical engineering at a local community college. He had plans to return to another college program in the near future while the younger son had recently completed high school and was making plans to enter college the following year.

Family "B" consisted of middle aged parents and three young adult siblings, two daughters aged 24 and 22 years and a son aged 18 years. Approximately 14 months previous, the eldest daughter had sustained a traumatic head injury when the automobile she was driving on a major highway in Eastern Ontario was struck by a transport truck when the driver failed to negotiate a stop sign. Following emergency treatment at the local hospital, she was transferred to the major trauma hospital where her coma lasted approximately four weeks. At three months post injury, she returned to the local hospital and several months later was admitted to a specialized in-patient head-injury rehabilitation treatment program. At the time of the family interviews, she was visited by her family once a week and was able to go home every weekend. At the time of the accident both parents were fully employed. The injured daughter had just graduated from a bachelors program and was enrolled for the following autumn in teacher's training, and the two younger siblings were university students. During the information meeting it was discovered that a youngest daughter had died ten years previous from a head injury sustained in a pedestrian-vehicle accident.

Following completion of the family interviews with both families, it was decided to include the data from Family "A" only. All family members were living in the family home and their son's accident was the first major tragedy in their family life. During the family interviews with Family "B" it was revealed that the previous loss of their youngest daughter ten years earlier continued to affect family life, especially for the parents. Thus, incurring a similar tragedy for a second time set this family apart. As well, family members were together only on weekends and holidays, since the injured daughter was in an intensive rehabilitation program and the other siblings were attending out of town universities.

Further factual information on Family "A" is included in Appendix B.

Research Process

Upon referral, families were contacted by telephone and a brief overview of the research project was provided to one of the parents. Emphasis was placed on the researcher's interest to hear each family member's perspective on how this event had affected their personal and family lives. The contacted parent was asked to discuss the project with other family members. If all agreed, an in-home family meeting was arranged at a time convenient to all family members where the project was described in detail and ample opportunity was provided for discussion, questions and personal concerns. At the first joint meeting, all participants were asked to read and sign the consent form (see Appendix A) and provided with copies of the McMaster Family Assessment Device (FAD) (Epstein, Baldwin & Bishop, 1983) used to assess and rule out severe family dysfunction prior to beginning the formal research investigation. Should severe dysfunction have been revealed, recommendations for professional help would have been provided in keeping with the university's Ethics Committee requirements. All members were given

copies of the written research questions and encouraged to provide detailed descriptions. The head-injured person was asked to complete a release of information form so that the researcher could obtain the medical discharge summary in order to ascertain the type and severity of head injury. In the case of Family "A", a parent was asked to complete this form since the injured son was unable to write or communicate. The first family interview was arranged to be held approximately two weeks later at the convenience of the family. It was requested that the written responses be returned prior to the scheduled meeting. Following the first meeting, the second meeting was arranged for two weeks later. All family interviews were video-taped and took place in the family home to ensure greater comfort and convenience for the family and to provide an opportunity to observe the family in their natural environment.

Written Protocols.

Each participant was asked to write or audio-tape (if unable to write) a response to two research questions. Responses were requested so as to situate and help each participant focus on the research task at hand. As well, responses were found to encourage personal reflection and expression in an unobtrusive format and to provide tangible descriptions upon which to begin the conjoint research interviews. The two research questions were formulated as follows:

Question 1: Give a detailed description of how your own or your son, daughter, brother or sister's head injury has affected your personal and family life. Please provide some specific examples.

Question 2: Describe in detail a specific situation that illustrates what it is like to live with or be a head-injured person in your family. The written protocols were analyzed according to the Giorgi's phenomenological method which is presented in detail in the Data Analysis section.

Interviews.

Two video-taped family interviews were conducted in the homes of each respective family in keeping with the research time frame. The interview format was semi-structured and discovery-oriented in nature, during which the researcher endeavoured to maintain a stance of openness and responsiveness to family member's willingness to share their own experiences. Overall, the interview process was guided by the fundamental question underlying the research project, i.e. what it was like to live with a head-injured person in the family. The researcher endeavoured to remain centred on the phenomenon being investigated in such a manner that she was able to maintain both a focus on significant details and an openness to the broader contextual picture. Furthermore, an effort was made to stay as close as possible to the family's lived-experience. This was facilitated by questions which asked participants to think of a specific instance, situation, person or event that might illustrate what they wished to communicate. On the other hand, patience and silence were at times found to be a more tactful way of prompting the participants to gather recollections and proceed with their story (van Manen, 1990). Wertz (1984) notes that "the procedure of data generation is a selective process whereby the researcher attempts to make manifest those aspects of the situation which are relevant to the research interest and faithfully express the pre-scientific matters under investigation" (p.38). Most importantly, the researcher needed to engage with the participants and demonstrate genuine interest, encouraging further elaboration of how particular experiences affected them. Here, the researcher's own personal experience of living with a head-injured daughter and navigating the medical and rehabilitation process helped attune her to family members' experiences.

Prior to the first family interview, the researcher read the written protocols provided by individual family members to identify basic themes affecting personal and family life that required further clarification. These themes were taken up and elaborated on during the family interviews. The first family interview began with a request for a description of family life prior to the accident. Describing their former family life provided family members with a safe forum, away from the sorrowful nature of the tragic accident, on which to begin their sharing of personal feelings and perceptions. It also set the stage for the temporal unfolding of the impact of the accident on their lives--their reactions to learning about the accident and the severity of their family member's injuries, and the effects of the accident on their lives in the days, weeks and months following this tragic event. Prior to the second family interview, the video-taped first interview was reviewed and areas were identified that required further elaboration and clarification.

Data Analysis

The data obtained from the written protocols were systematically analyzed according to the Duquesne four-step phenomenological method (Giorgi, 1985). The video-taped interviews were transcribed and significant non-verbal expressions were included. The transcribed family interviews were analyzed according to an adapted version of the Duquesne phenomenological method (Mook, 1986b, 1987; Emmrys, 1993).

The four-step phenomenological method described by Giorgi is as follows:

1. Sense of the Whole.

The transcripts were read to arrive at a sense of the whole. At this preliminary stage, written and transcribed protocols were read with an attunement to the phenomenon under investigation and the researcher tried to

get a sense of what the participant(s) was (were) really trying to say. This step served as the foundation for the next step.

2. Discrimination of Meaning Units within a Psychological Perspective and Focus on the Phenomenon Being Researched.

Meaning units were determined whenever the researcher became aware of a change or shift in meaning of the situation for the participant(s) which appeared to be psychologically significant. This required the adoption of a special psychological mind set or frame of reference where the researcher was sensitized to themes which carried psychological significance. As well, the researcher was required to "bracket" theoretical and personal preconceptions and presuppositions in order to be open to that which was contained in the descriptive passages. With the family transcripts, discrimination of meaning units centred on the spontaneously perceived subjective and intersubjective shifts including one or more participants.

3. Transformation of the Participant's Everyday Expressions into Psychological Language with an Emphasis on the Phenomenon Being Investigated.

Transformation of meaning units into psychological language entailed a cyclical process of reflection and imaginative variation. Imaginative variation involved imaginatively varying all constituents, implicit horizons, relations and themes composing the phenomenon in order to distinguish and disclose its essential features. As well, a sensitivity to the multiple aspects of the situation, such as temporal, spatial and social constituents and to how these aspects cohered and related to each other was required by the researcher. For the family transcripts, reflection and transformation into psychological language of the meaning units focused on personal, interpersonal and structurally meaningful constituents (Mook, 1987).

4. Synthesis of the Transformed Meaning Units into a Consistent Statement of the Structure of the Phenomenon Being Investigated.

This step centred on synthesizing and integrating the insights contained in the transformed meaning units into a consistent description of the psychological structure of the phenomenon. At this time, all transformed meaning units were considered and integrated. The synthesis of the transformed family meaning units also took the intrinsic interconnectedness between the subjective and intersubjective meaning-contexts into account in an effort to provide a coherent description of the basic structure of the phenomenon of living with a head-injured person.

Situated Structure.

The situated structures of the individual written protocols attended solely to the meanings of the individual's perceptions. The situated meaning structure of the family interviews, on the other hand, was attentive to the changes within family life while still respecting the changes to individuals but within the context of familial experience. Again, by the cyclical process of reflection and imaginative variation, the researcher articulated the invariant nature of the structure that emerged from the meaning units. Here a sense of the structural matrix of family life within the context of the phenomenon of living with a head-injured family member was revealed.

General Structure.

The general structure is the explicit formulation of the generality of the phenomenon derived from the situated meaning structures of individual research participants. Here, the researcher attempts to describe the essential nature of the psychological meaning of the phenomenon as it is lived. Because this research study centred on an in-depth investigation of only one family's experience of living with a traumatically head-injured person, it was not viable

to make any general statements concerning family life following a traumatic head injury.

In conclusion, the focus of the research project was to investigate the enduring significance of living with a head-injured person. We sought to illuminate the nature of temporal and spatial changes that emerged following the tragic event and how they affected personal and family life in general as well as relationships to self, others and outside world.

The results of the phenomenological analysis are presented in Chapter V. A final discussion follows in Chapter VI, including a discussion of dominant themes revealed in the research results, a discussion of the Heideggerian theme of care and its relevance to our research findings, as well as a dialogue with previous research studies, clinical implications, limitations of the research and implications for future research.

Chapter V

RESULTS OF THE PHENOMENOLOGICAL ANALYSIS

The results of our phenomenological analysis are presented in two forms: the situated meaning structures of each family member's written responses to the two research questions and the situated meaning structure of the two family interviews. The individual situated meaning structures disclose personal perspectives on how their son or brother's accident and resulting difficulties have affected their personal and family lives. The situated meaning structure that emerged from the analysis of the two family interviews, shows a temporal unfolding of the family's experience of living with a head-injured person and reveals a matrix of structural themes which will be taken up and presented in the discussion section.

In presenting the results, we have used alphabetical letters to represent family members: F for father, M for mother, S₁ for eldest (injured) son and S₂ for younger son. Additional factual information on our research family can be found in Appendix B. Analysis of written protocols and transcribed family interviews are located in Appendix C. Written texts and verbatim transcripts of the family interviews are located in Appendix D and are available on request.

Situated Meaning Structures of Written Protocols

First research question

Give a detailed description of how your son or brother's head injury has affected your personal and family life. Please include some specific examples.

Situated meaning structure of F.

Prior to his son's tragic accident, F and his wife commuted to work together on a daily basis. This was special for them as it allowed them to discuss and share a cornucopia of issues normally neglected while at home due to everyday household demands. Since their son's return home, F feels

there is less shared intimacy with his wife and their lives are lived more separately. Yet he also experiences a greater closeness to her due to their shared goal of caring for their son.

Since the accident, F and his family are no longer able to enjoy their customary weekend recreation time at the family cottage due to the physical difficulty of accessing it. For F, thoughts of the cottage bring back memories of his own adolescence and of introducing his sons to his special outdoor interests. Perceiving his injured son's need for his companionship along with a general lack of time and interest, F no longer engages in his favourite outdoor sporting activity (hunting) to which he had previously devoted a considerable amount of time and energy. He recalls how his injured son was a companion to him on his sporting adventures and he is painfully aware that his son is a grown adult despite the severity of his impairments. F also worries more about his younger son as the tragic experience of his elder son compounds his normal parental concerns.

Since their sons were at a stage of increasing independence prior to the accident, F and his wife were able to enjoy their own activities (flying) and plan for their future (retirement). F realizes that he cannot return to his former life and feels that other people do not understand this.

Situated meaning structure of M.

The foremost effect of the accident on M's life has been the psychological loss of her son, in particular his endearing qualities and their special relationship. She also mourns his personal loss of opportunities for normal life experiences. At the same time, she harbours a constant fear of possible personal illness or disability and the consequent inability to care for her son. This fear is most pronounced when she is away from her son, especially when

she is occasionally involved in the couple's special hobby of flying which carries an increased risk of an accident.

The mandatory termination of M's employment related to her prolonged absence has hurt her beyond words. As well, she feels isolated from relatives and former friends. She believes that the severity of her son's injuries limits interactions with others. To date, only a couple of close extended family members have shown interest and asked her what her everyday experiences of caring for her son is like. For M, life is now experienced in flux and is filled with worry over her care-giving competence. Future planning is foreclosed due to the uncertainty of her son's potential recovery.

Prior to her son's accident, M and her husband had decided to move back to the city in order to be able to pursue their special retirement hobby (flying). This would also have provided their sons with urban accommodation should they have proceeded on to college. Acknowledgment of the severity of their son's injuries and their decision to bring him home to a familiar setting compelled M and her husband to cancel their plans to move. Now, additional housework and upkeep also severely limit time for their special hobby. Prior to the accident M and her husband commuted together and shared a variety of activities. Now her husband is left on his own. As well, they have revoked their retirement plans in order to provide their son with the ongoing care he requires.

The coordinated caring demanded by their son's profound helplessness has resulted in a dramatic alteration to everyday routines which, in turn, has limited much of the former intimacy the couple shared. In addition, their son's total dependence prohibits their absence from home for any length of time. Continued urgings by others to take a break or vacation have been rejected because legitimate vacation time has been used for necessary professional

appointments (medical and legal) and more importantly, because their son's present condition nullifies any desire to do so.

Despite the tragedy and its consequences, M believes it has brought the family closer together, especially with their younger son. She believes he has developed a greater understanding of the depth and extent of their parental love. Caring for their injured son at home insures that he receives the best in personalized care and given these tragic circumstances, M feels they have made the best choice. She hopes their persistent efforts will benefit all family members in the future.

Situated meaning structure of S₂.

Though S₂ is resuming normal activities, he is affected by his brother's situation on many levels. Personally, he feels helpless in the face of his brother's plight. Awareness of the seeming finality of his brother's situation makes him feel sad and he feels guilt when he compares his own life possibilities to those of his brother. Given that their brotherly relationship was evolving to a more mature level of civility, S₂ imagines the potential for sharing and realizes this is now gone. He finds it hard to witness the dramatic change to his parents' lives and their increased concern and worry over both their sons. Special family trips are no longer possible, including visits with favourite relatives. S₂ worries about his ability to carry on the family's decision to care for his brother at home should this become necessary.

Research question 2

Describe in detail a specific situation that illustrates what it is like to live with a head injured person in your family.

Situated meaning structure of F.

Each day F is faced with the tragic reality of his adult son who is now defenceless, totally dependent and unable to communicate. Despite this fact,

he must go to work. Here he experiences the necessity of guarding his personal concerns and sorrows so that they do not intrude on his work or co-workers. Being sensitive to the present economic climate, F also feels pressure to increase his productivity.

F finds it is impossible for him to forget the tragedy that befell his family. He senses most outsiders expect that by this time his life should have returned to normal. He is astounded by the number of people who presume that involvement in his work helps take his mind off his familial reality. He is of the opinion that only the naïve could utter such a superficial comment. F's career and other interests are now of secondary importance in light of the gravity of this situation.

Situated meaning structure of M.

M describes a trip to a local museum to illustrate the time-consuming planning and preparation required when outings are undertaken. The day begins at dawn with M attending to her son's personal care and feeding. While father loads and secures their son into their specially adapted vehicle, M assembles the provisions and equipment necessary for the trip. By the time they arrive at their destination, three hours have elapsed. The tour must be scheduled around their son's feedings and they must be mindful of the time required for the return trip and resettling their son back into his bed.

Despite the lengthy preparation time (they spend twice as much time in preparation as compared to touring), M feels the benefits of getting out of the house. Moreover, she believes that the stimulation it provides their son far exceeds the effort required.

Situated meaning structure of S₂.

S₂ believes his brother understands much of what transpires around him despite his inability to speak. Unfortunately most visitors assume that being

unable to speak also means he is unable to understand. Consequently they usually exclude him from their conversations after a perfunctory greeting on arrival. S₂ attributes such behaviour to personal discomfort and ignorance of appropriate behaviour. The pain of witnessing this leads S₂ to sometimes wish visitors would not bother to come at all.

Situated Meaning Structure of Family Interviews

The situated meaning structure revealed that following the tragic accident, the family found itself abruptly dislocated from its ordinary, taken-for-granted existence in an everyday, unassuming world and thrown into an impersonal, medical-world. Their decision to bring their son and brother home for personalized caring initiated their attempts to re-claim and re-shape a new family life-world.

The disruption and disconnection of neural fibres became metaphors for family life in general. The family lived with a disruption of time and space and a disconnection from a world that was recently there for them as a backdrop to the unfolding of family life and experience.

This tragic turn of events effectively compromised the natural evolution of family development as it re-directed attention back to the present existential reality of their family. Here the existential call to care, and to preserve and nurture the innate being of each family member moved to the forefront of family life.

After analyzing the two transcribed family interviews, it was possible to identify three temporal phases through which the family moved in its experience of living with a traumatically head-injured person. These phases could be described as: the family's pre-accident life-world; living the immediate impact of the accident, including being-told, the hospital experience and the coming-home experience; and the family's readjusting phase.

Pre-accident Family Life-world

Prior to the car accident involving S₁, the family had reached a stage in their life cycle where all members were enjoying greater independence and freedom to pursue individual interests. Both M and F were employed full-time. S₁ had completed one year of college, was employed part-time, and had future plans to return to college. S₂ had recently completed high school and was considering various work and career options. Because of the close proximity of their places of employment, M and F usually commuted together and were often joined by S₁. Since their sons were now in the process of shaping their own lives and able to look after themselves, the parents felt greater freedom to come and go as they pleased.

Outside of work commitments, family life mostly centred around recreational activities. They spent most summer weekends at the cottage which had been in F's family since his adolescence. F was a sportsman with a keen interest in perfecting his skills as a hunter, and more recently, as an avid flyer of single engine aircraft. While S₁ and S₂ were more interested in pleasure sports, they occasionally accompanied F on hunting and flying trips. According to F, there were no major parental arguments or tensions over family-oriented activities. S₁ and S₂ were free to go their own way and always welcome to join in the family's activities. F recalls periods of filial rebellion during his sons' adolescent years, but after recalling his own adolescent years, he regarded their rebellion as a normal and necessary part of gaining personal independence. As a parent, his primary concern centred on the availability of education and training that would enable his sons to live independently.

Extrafamilial socializing, including contact with their extended family, was a low priority. According to M, they would never return to the city just to visit. S₂, however, was very social and active and had a wide group of friends and

interests. S₁ also had a group of friends and was involved with a girlfriend.

While M and F accepted and appreciated their sons' increasing independence, they recalled that S₁'s earlier departure to a nearby college was unsettling despite its relative closeness. F remembers the departure as less distressing than M. He seemed better able to appreciate his sons being on their own. M reports that the first night S₁ left was "terrible" for her. Consequently, she anticipated that the imminent departure of S₂, her youngest, might be even more stressful because it would signify both children's departure from home.

F was beginning to think about retirement. Since S₁ and S₂ were rarely home, he and his wife were spending a considerable amount of their free time enjoying their special hobby (flying) which they planned to pursue in earnest following F's retirement. Given the nature of their future plans, they had decided to simplify their living situation by exchanging their rural residence for a "maintenance-free" city residence. They believed living in the city would facilitate easier access to the airport. As well, it would also be financially advantageous, because it would allow them to provide city-based accommodation for S₂ should he decide to attend an urban educational institution.

S₁ understood his parents' desire to move and agreed with their plans since they "had been the best parents", but he also mentioned the possibility of remaining in the rural area. However, M believed that he was more amenable to their proposed residential change because he was working in the city and he was preparing to break off his relationship with his girlfriend. Unfortunately, S₂ was deeply distressed at the thought of moving. He had been raised in this rural setting from toddlerhood and did not relish the idea of city living. He preferred the greater privacy, the freedom of movement and the more relaxed social rules found in rural living.

M and F recognized that the age difference between their sons (five years) figured significantly in their reactions to moving. They perceived that S₁'s greater independence made him more open and receptive to his parents' future-oriented planning. On the other hand, they were aware of S₂'s distress over moving and also recognized that his life would be changing (e.g. he and his friends were all in the process of moving on to higher education). M and F deliberated for many hours trying to find a balance between S₂'s concerns and their own needs. They felt they had reached a satisfactory compromise with their willingness to provide S₂ with transportation to allow him to continue his rural friendships once they moved to the city. While the decision to move to the city was perceived favourably by most family members (exception S₂), they experienced a certain degree of ambivalence because they were still enjoying the peace, tranquillity and extra space of rural living. With the decision made, M and F planned to complete some house and property refurbishments and anticipated a sale within a year.

M had recently acquired a new job which she found delightfully challenging. With both sons in the process of establishing their own lives, she was becoming increasingly interested in her career and intended to pursue further training to enhance her skills and qualifications. Unlike her previous position where there was little recognition of her efforts, her new employer noticed and openly acknowledged them. As well, she felt strong support from her new colleagues. She was told she would be an "asset" to their work force. M loved her new job and felt space unfolding before her where she could devote time to career and personal development.

F, on the other hand, was shifting his attention away from his career to his pre-retirement interests. On a more personal level, M perceived him as a very sensitive and serious person, and not inclined toward superficial socializing or

chatting. All his efforts were thorough and once a decision was made, he tended to hold to his commitment. Prior to the accident, F reflected little on his role as a father, but does recall that he had always felt especially proud of being the father of his two sons. In retrospect, he realizes this perspective was somewhat biased but still holds to his steadfast pride in having two sons. In recent years, his relationship with his sons centred mainly on their shared interest in sporting and recreational activities. He considered them "his kind of boys" in that they enjoyed recreational activities that were charged with some degree of risk, e.g. motorcycling, skidooring. More importantly, his sons fulfilled his image of young males. Though F was aware of the potential for danger and sometimes worried about their safety, he sanctioned their participation in such activities assuming they were adequately prepared. He never anticipated his sons sustaining grave injuries primarily because he himself had never experienced a serious accident. Yet his sons were occasionally hurt. He vividly recalls an event which has returned to haunt him, i.e. S₁ returning home brandishing a bandaged arm following a motor sport spill and boasting of surviving another incident. S₁'s efforts to flaunt and minimize the situation made the situation worse for F. He recalls his anger at his son, but now recognizes it was a reaction of parental fear.

Prior to the accident, the sibling relationship between S₁ and S₂ was reaching a level of sharing and discussion. S₂, however, recalls intense conflict and fighting when they were younger, including occasional feelings of hatred. Typically adolescent, S₂ reports that their disagreements were sometimes "pretty brutal", but from a parental perspective, M emphasizes they were primarily verbal. She recalls frequently admonishing her young sons to "try to get along". She knew eventually they would be friends.

Married at a young age, M and F took their marriage vows seriously. Given their different dispositions, they had to work through their differences in order to grow into a more egalitarian relationship. However, they stress that this has not been easy. M considers that along with the fun and joy, raising children also required the acceptance and working through of difficult times. For her, their children symbolize their marriage vows and represent the commitment and caring they all share.

In describing the evolution of their marital relationship, F remembers the early years when he "laid down the laws of the home". While seeming humorous now, he recalls unequivocally and unabashedly decreeing that while he was willing to listen to M's viewpoints, should a stalemate arise, then "his word" would prevail. The turning point in the balance of power, according to F, was primarily due to M standing her ground. For example, on a significant occasion, F questioned M's desire to purchase a piece of personal clothing. Feeling dejected, she conferred with her mother-in-law who strongly advised her to hold her ground and take responsibility for her own needs. Subsequently M proceeded to purchase not only what she had originally intended but even more. From that time, the tenor of the household changed considerably.

In the years before the accident, M and F enjoyed a lot of shared time in commuting, sharing errands and flying. M especially remembers the Saturday mornings spent lounging and conversing over coffee. Their conversations ran from family issues, to incidental local issues, to complaining about work, and to everything in between. In this way, these Saturday mornings helped to release work-week tensions and to renourish their friendship since weekdays were focused on work responsibilities. As well, they each enjoyed individual recreation time to freely pursue special interests or sports. On a more personal level, F felt able to share the most intimate details with M and was never

uncomfortable talking about his perceived weaknesses. In turn, M reports she was never uneasy listening to him. Their relationship was one where they could be really open with each other. Despite having weathered their share of difficult times over the past 25 years, there was a special appreciation and valuing of their relationship. They felt they were "each other's best friend".

While communication between the marital pair was experienced as open, this was not the case with the rest of the family. F does not recall sitting and talking about feelings with his sons, nor did he encourage them to do so. He does believe that he would have if requested, despite his discomfort at initiating such conversations with them. Since S₂ was frequently off with his friends in a typical adolescent fashion, conversations with him were more likely to occur on his way in or out of the house. However, M and F note that a change in the family communication pattern had started to emerge just prior to S₁'s accident. Several months earlier, S₂ had witnessed the serious injury of two friends in a snowmobile accident that he himself was nearly involved in. He was visibly troubled, but talked little about what was bothering him. While M and F were aware of his distress (which they considered legitimate given the severity of his friends' injuries), they also recognized that he lacked the assurance to talk with them. In turn, they felt it would be inappropriate to approach him due to his obvious discomfort. Thus they felt they could only watch and be available for him should he decide to talk.

While family life was generally agreeable, family members were not reticent about openly expressing their frustrations and anger. Short outbursts were not uncommon. While M found S₂'s grumbling and fussing difficult to tolerate, she was nevertheless inclined to characterize his irascibility as part of adolescent immaturity. F, on the other hand, often took his frustrations out on his equipment (e.g. automobile, motorcycle). He rationalized this by saying that

his equipment was part of his collection of "toys" and not permitted to let him down. In recalling some of these explosive incidents, M suggested that men and women seem to experience and act upon their frustration in different ways.

Despite the growing independence and autonomy of all family members, F firmly believes that they all experienced home and family life in a positive way, e.g. comfortable, and relatively supportive. Importantly, home was a place always open to all of them, especially in times of need.

Living the immediate impact of the accident

In reflecting on the events surrounding the accident, M and F recall that they focused primarily on specifics and doing what had to be done. On the evening of the accident, S₂ was out with friends and S₁ had been invited to visit a new acquaintance (driver of the automobile).

A few hours after S₁ had departed from home, M answered the telephone call from the physician at the local hospital. Initially she did not accept the news of the serious accident believing instead that it was either a joke, or not possible, given the shortness of time since S₁'s departure. The reality dawned when the news was repeated, and she was told that S₁ was being air-lifted to the city trauma hospital. M asked if S₁ was "going to make it", but the physician was unable to provide an answer. F sensed the seriousness of the situation from overhearing the telephone conversation. Few words were spoken and M and F immediately prepared to leave for the city hospital. Before departing, they tried to locate S₂. When this was unsuccessful, friends offered to find, inform and care for him until his parents' return. By chance, S₁'s girlfriend called and they informed her of the situation.

M remembers all activity was "automatic" and consisted only of essential preparations with very little talking. The distance into the city felt like the longest time in her life. For F this was a time of "stunned disbelief". They held hands

throughout the drive in an attempt to "hang onto the other for dear life". M felt as if "her whole world had caved in". Though F sensed the seriousness, he simultaneously also feared to imagine the possible extent of his son's injuries. He realized the factual situation would be forthcoming only when they arrived at the city hospital. Until then, they were suspended in the realm of the unknown. The situation was aggravated for M and F by not knowing where S₂ was. They desperately wished he was with them in order to help reassure them of his existence and his well-being.

Ironically S₂, while on his way to visit friends, had inadvertently come upon the remains of a serious vehicular accident. He recalls his shock on seeing the damaged vehicles and imagining a fatality. Returning later to his best friend's home, he was urgently summoned and informed of his brother's accident. While detailed facts were unavailable, S₂ was informed that his brother had been "air-transferred" to a trauma hospital and that his parents had left for the hospital. S₂ remembers feeling confused, initially thinking his parents were the ones involved in the accident. Momentarily S₂ also believed it might be a joke. Given the uncertainty of the situation, S₂ stayed at his friend's home overnight, waiting for his parents' return.

Both parents remember the confusion during the early hours at the hospital. Upon arrival they had to identify their son because of a health card mix-up and the admission of another person with the same name. For a split second M thought the seriously injured person might not be her son, but deep inside she knew it was.

Waiting and more waiting dominated their time at the hospital--waiting for S₁ to be transferred from the operating room to intensive care and waiting to talk with the attending physician. S₁'s girlfriend and her parents were there in the beginning but departed after several hours when no information was

forthcoming. Until the arrival of the medical expert, M and F could only wait and hope. Late in the night, the attending physician finally met with them and described their son's condition as very grave--severe head injuries and coma, as well as a possible shoulder fracture and internal injuries. Before leaving, he told them their son might not survive the night. M recalls little emotion on seeing S₁ in the Intensive Care Unit following the meeting. Not until a short time later did the tears appear. F initially insisted they call their respective families and then return home as soon as possible because he felt an urgency to "see S₂ and have him with us". However, they quickly discovered that returning home was temporarily impossible because of their severe emotional distress. They stopped at F's parents to regain some emotional stability. M acknowledges that their arrival in the small hours of the morning was unprecedented and their news shocking. Nevertheless, to this day she is still bitter over the unemotional response shown by F's parents that night. M and F returned home before dawn and were rejoined by S₂ a short time later. Together they returned to the hospital early in the morning.

The family spent the early weeks in the city, staying with S₁ from late morning until mid-evening and lodging with F's parents at night. Their focus was to be with S₁, hoping desperately that his coma would lighten. Breaks in the routine occurred only when attending to practical matters such as buying clothes for S₂, or for post-accident related meetings with lawyers and insurance agents that were becoming increasingly necessary. M and F did not return to their jobs during this time, and work-related difficulties soon started to emerge for M regarding her request for unpaid leave from her job. While M and F were preoccupied with being at S₁'s side throughout the day, S₂ found this time exceedingly long as he was neither at school nor employed and he had recently met a new girlfriend whom he wished to see. After a few weeks, he

started returning home on weekends. After a month, M and F started returning to their own home in the evenings. During the remaining three months of S₁'s hospitalization, M and F spent their days with S₁ and returned home nightly, exhausted. Since S₂ cared for himself, they used their home solely for eating and sleeping, and to organize the coming day's events including work-related issues if required.

At the outset, the family believed appropriate medical intervention would be forthcoming for S₁, as well as the effective management of any required services. Referring to the lack of intensive intervention for persons in coma, F vehemently states that there was "nothing there to help us". Thus, they felt forced to rely on their own resources. He recalls how they took it upon themselves to research the nature of S₁'s condition and its sequelae. However, as they became knowledgeable about progressive therapeutic treatments, it quickly became painfully apparent that such treatment was not available at their treatment facility. In response, they took it upon themselves to do all they could for S₁ to make up for this absence. Their new found knowledge informed them that the first weeks and months were critical. They learned it was urgent to try to reduce the duration of the coma in order to maximize the potential for a positive outcome. F reports he had forgotten that helping S₁ during his time of hospitalization almost took over their lives. They were totally preoccupied with helping him as they urgently searched for ways to stimulate S₁, hoping to reduce the duration of his coma.

In the early days of S₁'s hospitalization the family held certain fixed ideas about medical experts, for example, that they would be strongly committed to providing injured persons with the most appropriate and effective care. F was shocked when he suddenly realized that these experts (professionals) were not as concerned about their son's health as they were. He was also mystified by

the staff's lack of understanding for their feelings. Naïvely he expected that they would be more understanding of family members' feelings and concerns since they worked with families in tragedy on a daily basis. Gradually, the parents began questioning their earlier presuppositions regarding health professionals, and over time, tension between family and staff increased. From their perspective, it felt as if they had to fight for any care that was outside of standard practise. This feeling led to the perception that they had to "fight for everything". Over time, the family found they were becoming increasingly frustrated with the hospital situation and their son's care. In the early days following the accident, they had anticipated S₁'s transfer to a specialized local rehabilitation centre. However, they soon realized that, given his slow rate of progress, he would not qualify for placement for sometime. When his condition was declared medically stable despite the persistence of his coma, his parents realized his transfer would not occur in the foreseeable future. They felt "bringing him home" was their best solution. For them, it was natural and indicative of their commitment to him, for they simply could not accept the alternative which was to place him in a chronic-care facility.

M and F were convinced that home was the only place they could guarantee specialized loving care for S₁ and ensure control over their situation, i.e. the need to provide an appropriate environment. M recalls that having at least some control was of paramount importance. They felt they had lost control over everything after the accident had occurred. F firmly believes there was unanimous agreement among family members in their decision to bring S₁ home. The parents felt this decision would also benefit S₂ because they would be home for him in the evenings. He corroborated this perception and recalls his heartfelt approval of his parents' plan to bring his brother home. He remembers often being home alone while S₁ was in the hospital and it seemed

as if "no-one else was ever home". With the return of his family, S₂ also felt he could be assured of his brother's whereabouts and well-being. To M and F's surprise and consternation, certain health professionals questioned their rationale for bringing S₁ home, pointing out the disruption which would, in their view, occur to S₂'s life. M found this attitude puzzling because from her perspective, being home together seemed decidedly better than their being at the hospital for hours on end while S₂ was on his own at home. Having control over S₁'s care and care providers became the most compelling reason for "removing S₁ from the hospital".

F believes they understood their new reality rather quickly. He recalls that early on they had realized that their lives "had changed forever" and there would be "no going back". Intuitively they seemed to fully realize the severity of S₁'s injuries. However, rather than dwelling on how their life-world had changed, their attention was riveted on helping S₁, i.e. contending with his care to maximize his recovery process, and making the necessary household adaptations to accommodate his needs.

M found that her life-world had suddenly and dramatically changed. Work lost its importance and her job became irrelevant. This was surprising to her given the recent pleasure she had derived from her work. Her focus of attention was now primarily on helping S₁. During the early weeks of his hospitalization, she experienced a desperate need to be with him and to help him. However, with the passage of time and their growing dissatisfaction with what they thought to be insufficient rehabilitative care, M and F's most pressing desire shifted to being able to bring S₁ under their own care and give him their best efforts.

While both parents were distraught with worry over their son, M feels F found the experience even more distressing. She suggests that this may be

because men have traditionally been reared to believe that they must provide for their families, and in this situation F was "stripped of this control" and there was nothing he could do to alter the situation. M sensed that he was also "more victimized" because the attitude of hospital staff and nurses seemed to be condescending toward him. She recalls how they seemed to question F's profound concern and continued presence at his son's side, and that they insinuated that he should behave more like "a normal father", i.e. go to work and not be so involved. While M perceived a tolerance for her presence, she nevertheless felt they categorized her as a "neurotic mother" who is overly concerned and therefore allowed to be with her child. M also detected an attitude from hospital staff that seemed to imply that she and her husband were wasting their time. She sensed this was directed more toward F and was coupled with a desire to be rid of him so they would only have to deal with her. She speculates that this may have been partly due to a fear of their joint strength.

Though aware of F's predisposition to fret under certain circumstances (e.g. waking in the night with worry), M was struck by his reaction to the staff's apparent attitude towards him. During S₁'s hospitalization, F's natural sensitivity to others was heightened and he became increasingly distressed by his son's condition and the apparent lack of appropriate rehabilitative treatment available to him. F recalls that this stance of heightened sensitivity emerged naturally "like a basic instinct". He was fervently mindful of S₁'s age and to this end, he feared demeaning treatment to his son in view of the severity of his injuries. Consequently, F felt compelled to do everything he could to protect his son's dignity and manhood.

M was not surprised by the effect of their son's accident on F. From the time of their sons' births, she had been aware of his special concern for his

children. She recognized that his emphatic assertion: "This is my son, he's 22 years old", was his way of saying that this was his young adult son who needed the male presence of his father, and that he also needed to be there with his son. Witnessing the distress F experienced from his treatment by hospital staff grieved M terribly. She wanted to scream at the staff to recognize that F's presence was as important as hers, maybe even more so given that father and son had recently moved to a more mature male-sharing type of relationship.

While the parents were mostly preoccupied with concern over their injured son and their relationship with hospital staff, they also became aware of a surprising change in S₂. They realized that he held his ground with hospital staff and insisted on his right to be with his brother as much as he wanted, and to observe his brother's specialized care. He also remained undeterred even when glared at disapprovingly by nursing staff for his presence during certain medical procedures and held steadfast to his determination to stay with his brother. Of special significance to M and F was the apparent impact of S₂'s presence on S₁. Despite the severity of S₁'s coma and even during his lowest time, the sound of S₂'s voice and his presence during his weekly visits seemed to trigger a response from S₁. He would often strain to orient himself to hear S₂'s voice. M attributed this reaction to the bond between the brothers.

Once the family decided to bring S₁ home, meetings were arranged to discuss his discharge and to coordinate the transition between hospital and home. Necessary arrangements had to be made including house renovations and a comprehensive home-based rehabilitation plan. Given S₁'s profoundly impaired state, making arrangements for his transfer home was fraught with complications, and heated arguments often ensued between family and hospital staff. The interdisciplinary team's insistence on ironing-out details was often interpreted by the parents as inordinately time-consuming. They became

increasingly impatient to have their son home. During one significant meeting, tension and frustration rose to a point where the family's patience broke and they decided to take the situation into their own hands. They would take their son home by their own means if necessary and they would care for him on their own. Something happened that day, the decision was made and their resolve became unshakable. As a result, the necessary arrangements slowly fell into place. With the decision and time frame firmly in place, M and F used the remaining hospital time to train themselves through observation and practice, to care for S₁, to familiarize themselves with the necessary equipment, and to begin to understand what it would be like to be totally responsible for S₁'s care.

While the family's underlying goal and purpose in bringing their injured son home was to provide a measure of control over his care and how it was provided, they soon found the road filled with obstacles. At home they believed they would be able to accept, direct or reject the professionals assigned to provide specialized in-home care for their son. In the beginning, S₁ was provided with rehabilitation and nursing services that were coordinated by a rehabilitation company which had been arranged for and provided by their insurance company. The family's initial assumption that this company would coordinate the provision of needed services (e.g. physiotherapy, speech therapy, nursing, equipment, supplies), and would serve as a resource of expertise, quickly soured. Unhappily they learned that the service entailed a total management package that not only included S₁'s daily care but also encroached on their own everyday family life. In addition, they were obliged to either accept or reject this arrangement. Considerable dissension ensued and the ultimate affront occurred when they were told they lacked the specialized knowledge they thought they had achieved. This led to the dismissal of the service provider and in turn M and F took control over the total organization and

management of S₁'s care. During the early months of their leadership, there was a considerable turnover in specialized care providers. Only those who demonstrated a compatible attitude towards S₁'s care, along with the necessary competence, were retained.

Currently both M and F are in charge of planning S₁'s care. M serves as the primary co-ordinator of care and initiator of service acquisition, while F oversees the financial resources that provide for specialized services, supplies and equipment not covered by traditional health insurance. Given their son's need for 24-hour monitoring and care, the routine of everyday home-life has been dramatically altered. M is home on a full-time basis and shoulders the entire burden of overseeing and providing S₁'s personal care with selected professionals who provide specialized care when required (e.g. physiotherapy, speech therapy and periodic nursing care and rehabilitation consultations). F has resumed his work but shares in his son's care in the evenings and on weekends. During the early months of their son's return home, M and F slept in his room to insure his personal safety. They alternated their sleep time with F retiring first to guarantee some uninterrupted sleep, and M following after attending to S₁'s late night needs. With her retiring after midnight, exhaustion ensured a deep, unrousable sleep. She was grateful that F was then able to take over and his fine-tuned alertness allowed him to wake at his son's slightest move. The couple no longer share sleep time nor early morning pre-work time together. While they sorely miss their former intimacy and shared time together and their lives seem more separate, they do share a common goal. Both see that "there's something that's come up that is much more important". Since M is home on a full-time basis, she is available for S₁ throughout the day and also for S₂ and F when they return from their day at school or work. All are present

at dinner time, and M makes sure S₁ is in his chair at the table so that family togetherness is ensured.

The Family's Readjusting Phase

Bringing S₁ home initiated the family's struggle to regain and rebalance their familial and personal lives. We see a family whose central focus has shifted from the development of individual interests and independence to providing the best care possible for their injured son and to reconstituting a cohesive sense of family.

For M, the care of her injured son and her family has become her central concern. Her prior interests in career and personal development and the exploration of a more leisure-oriented pre-retirement world have receded into the background. She now finds herself back at home in a dramatically altered role of mother and primary care-giver. While her present role is similar in many ways to the stage when her children were young, it is also very different. She now feels called to provide more than ordinary mothering, to "be there" for her family and to be the "core of their home".

With the accident, M lost a close and special friend in S₁. She deeply misses their special joking and camaraderie and she poignantly recalls that "he would have done anything for me", not in expectation of a return of favours, but more as a tribute to the specialness of their reciprocal relationship. As well, M has lost much of the close and personal shared time she once had with her husband. The recent series of tragedies experienced by her younger son has changed the fabric of their relationship as well. She now worries about his emotional well-being and feels her availability and support is vitally important.

The loss of M's career has been particularly painful and grievous. Tearfully she reveals that being denied a leave of absence from her employment on compassionate grounds following standard request procedures

has affected her to an extent she believes no one could ever understand. She recalls the day she received the formal decision several months after S₁'s return home. In the administration's letter, they reiterated their belief in their fair treatment (i.e. granting her an additional three months of unpaid leave) and reminded her of her own responsibility in terms of abandoning her position (i.e. failure to return to work). This felt like the "ultimate blow" to her and she remembers feeling tremendously bitter at that time. She wept the entire afternoon and then vowed to "cry for no one again". She pledged to F she would never return to the work force. She attributes her vow to the lack of compassion and support received from those she believed would value her caring for a tragically-injured son until their living situation settled down. M felt "something died in me that day".

Assuming the primary responsibility for S₁'s care has provided M with some control over how her son is cared for. It has also brought forth a previously unseen dimension of M. F recalls that there had been nothing in their life together before this time that ever demonstrated her "in control, fighting side". While he knew she was a sociable and determined person, he now sees how her social acumen, when coupled with her persistence and stalwartness, enables her to effectively negotiate the ongoing interpersonal interactions required to ensure quality care for their son. While she feels that she has had to extend her care-giving role to include being a protector and a buffer between her family and the outside world, she also feels a sense of satisfaction in being able to rise to the occasion.

M also shows that she can be exceedingly particular about S₁'s care even to the point of annoying F at times. Her fine-tuned vigilance leads her to notice when things are amiss, and then she insists on immediate correction. F finds her sensitivity and awareness of S₁'s needs remarkable. He can only

attribute this to her previous nursing training and the experience she had caring for him during a prior disabling back injury. However, below her apparently strong and in-control demeanour, M has experienced another facet of her character which came as a surprise to her. She vividly remembers incredible outbursts of emotion during the early months of S₁'s return home, especially before house renovations had been completed and her son was confined to the living room. She recalls "literally exploding" for seemingly trivial reasons and notes that considerable anger-induced damage to the house and household items occurred. She still recalls the frightening nature of those moments when she realized her potential for violence. Over time, she has discovered several strategies to help redirect her anger, but concedes that when frustration over acquiring specialized care or equipment for S₁ emerges, anger is sure to be evoked.

Presently M leads a lonely and solitary life and feels disappointed by most relationships. She feels let down by a world which she thought would be there to help her, i.e. family and friends who would understand and offer emotional support. Many of those she most expected to be of greatest assistance seem to provide the least, while at times complete strangers show genuine compassion. Outside of her own mother, only one extended family member has cared enough to ask what it is like for her to care for S₁. Occasionally she ponders the rationale behind the neglect of others in an effort to maintain some faith in humanity. Nevertheless, she is deeply saddened by the apparent lack of interest shown by others and she believes this contributes to her own lack of interest and patience to engage in social interaction.

F's primary interest also centres on his son and doing things which might help him "have a life" despite the severity of his injuries, e.g. talking and sharing time with him. To this end, F has experienced an intensification of his parenting

role and a heightened sensitivity to the situation in which he finds himself. Reflecting on his role as father, F recalls how his sons had moved through the stages of male development: from the safe proximity of mother's care, to looking to their dad for male guidance, and finally to a stage of greater maturity and mutual sharing. Suddenly S₁ is back home and totally dependent. F feels his role has reverted to being a guardian and provider again. He finds this role very demanding, and while in some ways similar to when his sons were small children, he now also feels compelled to not only protect his son from harm but also to shield him from a society that he perceives as a threat to the severely disabled.

Despite F's realistic knowledge of the ramifications of his son's accident, he still fosters a silent hope that one day S₁ may be able to enjoy a certain quality of life. From his perspective, this means male-oriented interests and activities appropriate to young men of his age and his level of functioning. F endeavours to be with his son as much as possible. When at home, this includes staying with him whenever M is occupied, watching television together, taking him to places of interest (e.g. the museum, a marina or airstrip), or having S₁ with him in the yard as he attends to outdoor chores. F regrets that his time with S₁ is limited to evenings and weekends. Having to leave his son each weekday is heart-wrenching for him. His distress is exacerbated by the lack of understanding expressed by others, especially those who assume that his work provides him with a diversion or respite from his despair over his son's condition.

To metaphorically illustrate what he experiences on a daily basis, F relates a rescue drama presented on television where a young girl was swept away in a flash flood in a drainage ditch and a neighbour attempted to rescue her. Hanging onto a branch over the fast-moving water, the neighbour

extended his arm to the girl in an attempt to grab her before she was swept downstream. Each day F painfully feels he too is reaching and straining as hard as he can, extending his arm but unable to reach. He feels powerless to "change things or make things happen". While F wishes he could find something to "trigger a positive change" and strives on a daily basis to find ways to help his son, he feels he never quite succeeds. He continually lives in this manner and admits he simply cannot stop trying. In addition, F compares their situation to living with chronic pain where solutions for relief are not forthcoming. From his own experience with back surgery, he clearly remembers being told that all they could offer him were strategies in learning how to mentally deal with the pain. At the time, he felt "this was a terrible way to live", and now compares it to their present situation.

F feels his relationship with his younger son has been relatively unaffected by S₁'s accident. He sees S₂ as an independent person doing the things he wishes to do (i.e. school and friends). He wistfully observes that the reality of his own situation is such that there is little time for shared activities with S₂ given his work responsibilities and his commitment to S₁. Furthermore, he believes he does little of interest to warrant S₂ joining him although they do fly together on rare occasions. Recalling the previous year, F remembers the enjoyment he derived when S₂ commuted with him, even when they had to accommodate each other's diverse music preferences. Though he presently misses this time together, he nevertheless believes driving separately better serves S₂'s study needs because he is able to return home at his convenience. In thinking of S₂, F reveals his fear that "lightening can strike twice". Deep down, he is afraid that he has "one (son) down and maybe one more to go", and reveals how the fear that something may befall his second son never leaves him.

Since S₁'s accident M has noticed what she calls a "magnification" of F's sensitive and serious nature. This change has been beneficial because it enables F to be sensitive to the minute alterations in S₁'s behaviour. When present, he is always trying to help S₁ be more comfortable or find something interesting for him to look at. In the extreme however, it leads him to worry unduly about the quality of S₁'s care. At times he even worries that S₁ is neglected during the day when M has to attend to frequent telephone calls. While he fully understands the importance of most of these calls (most are connected to providing more effective care to S₁), he nevertheless fears that S₁ is temporarily left alone and his rehabilitation is being neglected. F has also become more aware and responsive to the plight of other disadvantaged individuals. He feels a strong responsibility to be a vocal advocate on their behalf. Moreover, he finds that he is easily offended by the omissions and inappropriate comments of others. To this end, he often feels the need to fight back in some way.

The pervasive presence of anger F experiences in his life worries him greatly. Not only must he deal with everyday frustrations, he now finds himself thrown into a situation with a new set of rules and expectations and a system which has the power to control their ability to care for their son. F feels they must walk a fine line between directing their anger in constructive ways and controlling their anger in order to avoid excessive stress. He has suffered many anger-induced "sleepless nights", as well as nights filled with violent dreams which he understands as his attempts to maintain control over his anger. He finds he is particularly upset by those who assume his life should be back to normal given the passage of time. He cannot understand how anyone could believe he could forget his son's situation at home while he is at work, or that he

could have the time or interest to leave S₁ to participate in recreational activities.

F feels a tremendous responsibility to fight for his son, i.e. for specialized care, equipment and funding. This came as a surprise and bothers him considerably. He naïvely assumed adequate expertise and resources would be available to them when his son was first injured. Instead he found "there was nothing there to help us we had to use our own imagination and put up with a lot of flack". F holds a great deal of bitterness that he finds difficult to dispel.

As part of F's new parenting role, he also shoulders the responsibility of managing the insurance fund that provides for S₁'s rehabilitation needs. Given that this fund is finite, he feels a responsibility to be knowledgeable of the high cost of procuring local rehabilitation services, as well as the availability and costs of specialized treatment programs in the U.S.A. and Europe. It angers him that many services are classified as purchasable services. He constantly worries that recent and rumoured cutbacks to health and social services will further deplete their fund that must last for the rest of S₁'s life. Consequently, he feels pressured to be judicious and prudent in his decision making.

Since the accident, F has been faced with a dimension of the outside world he had never encountered before. While he is able to appreciate the reluctance of some people to inquire about his son's progress and his well-being, he finds the general lack of understanding and insensitive assumptions made by most outsiders distressing. Furthermore, he is deeply insulted by those who believe they have new-found wealth resulting from the insurance settlement awarded to S₁.

S₂ is outwardly moving ahead with his life. He is presently enrolled in a college program, has summer employment, a circle of friends he socializes with, and a girlfriend. Nevertheless, he feels he is always waiting for another tragedy

to occur. He believes this is related to the series of near-fatal and fatal events involving his brother and several close friends in the space of one year. He finds it difficult to articulate his thoughts and concerns, and feels unsure of his ability to cope with so much. He worries if he will be able to "keep his sanity" as his emotions seem to be so close to the surface and so easily disturbed. His parents are aware of his deep distress and have made a concerted effort to be open and available to him, understanding the enormity of such events for a person of his age. S₂ acknowledges their responsive attention and support and strikingly remarks that "they are like my own personal psychologist". Together they have struggled through S₂'s "ups and downs". He reveals that since his brother's accident he feels closer to his parents, often preferring to be with them rather than with his friends, especially after the death of his best friend.

S₂'s unresolved distress goes deeper. He reveals that after being faced with the first tragic accident involving his friends, he found that alcohol helped alleviate feelings of anguish and helplessness, but this in turn led to excessive consumption and a consequent dependence. Unfortunately the alcohol also fuels his anger and intensifies extreme shifts in his emotions (e.g. rage, sorrow, despair) to the extent that he now fears that if his anger escalates, he might literally inflict fatal harm on someone. On two recent occasions, he felt dangerously close to acting on his emotions (i.e. wishing to inflict fatal harm), but fortunately the situations did not erupt into violence. Reflecting on these situations, S₂ realizes that invariably these angry outbursts are triggered by insensitive remarks made by others about his brother or others who have also suffered misfortune. S₂ is deeply troubled by his surging emotions and wishes he was able to avoid his need for alcohol.

M and F are aware of S₂'s low tolerance for alcohol and realize his precarious situation as he attempts to come to terms with the past traumatic

events. They worry not only about his distress but also about the effect of his drinking on his behaviour. They especially worry that he will drive while intoxicated. However, they note that in recent months there has been a gradual decrease in S₂'s excessive consumption of alcohol. M attributes this to the purchase of a new automobile for him, as well as to his sensitivity to his parents' strong concern for his well-being. They hope that their efforts to impart a sense of responsibility for one's actions, and avoid "foolish" behaviour or, as F says, "avoid doing something you will have to apologize for later", will help S₂ modify his behaviour.

M and F understand that behind S₂'s "face of an angel" dwells a person who bottles up his feelings which occasionally erupt as a result of frustration and everyday anger. In response, they purchased a punching bag so that he could legitimately express his emotional anger in an appropriate way. He has found the bag to be extremely helpful. More importantly, they encourage him to verbally express his feelings with them. F has openly shared his empathy over the anger S₂ feels, indicating it is similar to his own. He hopes that his example of expressing his feelings and concerns in the safe environment of home will help S₂ appreciate the acceptability to do likewise.

As a marital couple, M and F have lost a lot of independence and opportunities to develop new interests. Yet they hold firmly to their belief that this tragedy has actually brought them closer through their shared commitment and caring for their sons. F believes their relationship has evolved to a higher level of understanding which in turn enables them to willingly devote their time to caring for S₁. M admits that to her surprise and satisfaction, she and F seem to be "pulling in the same direction" with a similar degree of conviction. Reflecting on the strength of F's concern which she believes parallels her own, she observes that these strong feelings often go unnoticed so that most people

do not realize the strength of their need to protect and survive. M further imagines that an opposite situation could have occurred in which they opposed each other, leading in turn to conflict. Without F's commitment, M realizes she would have felt compelled to shoulder the entire burden.

F shares a reciprocal appreciation for the care M provides. Though he feels fortunate, he fearfully wonders how he would have ever managed had she "not been the kind of person she is". While he has always admired M's social abilities and at times has wished he was more like her, he now recognizes the tenuous situation he would find himself in should she have been unable or unwilling to rise to the challenge. He acknowledges his own limitations, especially the necessity to be at work each day, which prevents him from helping M in her many tasks and the interpersonal interactions she attends to. He recognizes her proficiencies and strives to support her as much as he can.

As parents of a profoundly disabled young adult son, M and F are continuously concerned about the adequacy of his care, and whether their efforts are maximizing the possibility for even a limited degree of recovery. Given the severity of S₁'s condition, conventional rehabilitation treatment is as yet insufficient. Other more intensive programs are not locally available. They must struggle to put together in a piecemeal fashion a rehabilitation program calibrated to S₁'s specific needs. F occasionally worries that their decision to manage the organization of their son's care may have been wrong. He wonders if they are missing or overlooking useful resources. M, being focused on the practical everyday aspects of S₁'s care, is quick to reassure him that they themselves are perfectly capable of investigating and procuring needed resources, equipment and services. For her, the problem is that there is little rehabilitation knowledge available that applies to persons who are as disabled as S₁ is. Given his present status, M feels they are primarily on their own and

forced to manage as best they can. Consequently, she is firmly convinced that if she is not able to direct S₁'s care, no one else is available to co-ordinate such a specialized program.

Slowly M and F are re-defining their familial reality to include the caring of S₁ as an inseparable dimension and central focus. Gone are the days of coming and going at will, gone are the days of contemplating a move to a hassle-free city house, and gone are the days of open-ended dreaming about retirement plans.

Despite the anguish and despair suffered by this family and the ongoing challenges they face on a daily basis, they easily identify the factors that are helping them persevere in the face of such a tragedy. According to M and F, the cornerstone underlying all their efforts is their shared conviction and commitment to caring for their injured son. Together they are resolute in their determination to seek out and provide the best and most compassionate care possible. They also experience a relative absence of familial conflict. Their younger son seems to have a good understanding of his brother's need for the time-consuming care provided by his parents.

The opening up of communication and dialogue between family members has been identified by M, F and S₂ as the most significant change to family life. All major decisions pertaining to family life are now joint decisions. S₂ has been included in all stages of the decision-making process (e.g. bringing S₁ home) which was not the case before the accident. In addition, M and F have made a concerted effort to provide an emotionally safe environment for S₂, and to be open and available for him. They believe that their own willingness to express their despair, pain and frustration following the accident have helped legitimize the expression of personal pain and grief in the family.

As well, they have endeavoured to share their understanding and empathy for S₂ and the tragic events he has witnessed.

What the family finds surprising and difficult to cope with is the prevalence and nearness of anger. It seems to lurk just below the surface, appearing at the first sign of adversity. As well, it often triggers the resurfacing of old unresolved anger (e.g. the perceived lack of interest or caring by others). The common predisposing feature of most of their outbursts of anger seems to stem from insensitive and trite comments from outsiders, and from the obstruction of S₁'s care and protection. M and F have found that being able to secure necessary services and appropriate accommodations for S₁'s care has helped reduce individual and family tension and consequently subdues angry feelings. Over time, they have learned the necessity of mobilizing their efforts to maximize availability of resources. Now they feel they must be constantly vigilant in order to detect any slip or gap in services so that they will be ready to react when necessary.

M and F realize that in some ways their anger is necessary and beneficial because it fuels their efforts to defy the odds and try to help further S₁'s recovery process. On the other hand, anger is also a primary source of personal stress. F, in particular, is concerned about the effect of living with high levels of anger over time. Inside the home environment, everyday life is often far from harmonious because family members tend to express their pent-up frustrations when situations deteriorate. However, since S₁'s accident, family members are more able to empathize with other family members, and realize that releasing anger may be unavoidable at times. They have somehow learned to avoid the urge to retaliate when at the receiving end of another family member's wrath and recognize that each is entitled to be who he or she is. While the expression of anger is condoned, it is also understood that it is not a

licence to damage material goods. Due to a greater openness in communication, family members usually understand that it is their unique situation which precipitates most angry outbursts. Despite these outbursts, which are diminishing over time, unmitigated support and open dialogue exist between family members. This, in turn, provides the foundation for a special family cohesiveness.

Since S_1 's accident, family life has become severely constricted in that caring for the family in general, and for S_1 in particular, has become the centre of their attention. Recreational activities, weekends at the family cottage, vacations and individual pursuits are virtually non-existent. While S_2 is more involved than his parents with outside activities, he is forever mindful of his brother's situation. He makes a concerted effort to talk with S_1 and tell him of his activities and plans. On the other hand, M and F have no desire to leave their son, and find it conceptually impossible to disengage themselves from the worries connected to him and his care. They strongly resent those who encourage them to take a break or vacation. Instead, what they fervently desire is to find ways that could allow S_1 to accompany them on a vacation. Besides, legitimate vacation time has been all used up by medical appointments, legal and professional meetings. Occasionally M and F still fly together, but M notes that each time she has been plagued by air-sickness and she wonders if it may be related to her profound fear of an accident which would prevent her from being able to care for S_1 . Even when she is away from home on an errand, she invariably worries about her safe return.

Since S_1 's accident the family's social world has been dramatically altered. Outside of their immediate family and M's mother, only several professionals who remain involved with S_1 's care, as well as a few outsiders who have experienced similar situations and show compassion and

understanding, figure within their life-world. Basically, these are individuals who have some sense of what this family is experiencing. The family consequently experiences life as lonely and isolated. M and F have chosen to disregard the comments of many as a form of protection, but this makes them feel alienated and disconnected. At this point, however, they feel it more prudent to distance themselves and avoid those who they feel obstruct their present well-being. F suggests that the lack of understanding they experience from others and their need to erect protective barriers may underlie their increased awareness and appreciation of the importance of their own sense of family. In this way, there seems to have been a distillation or purification of the notion and experience of what being a family is about.

Believing they might further society's awareness of the plight of families like theirs, the parents agreed to participate on a television "talk show". Here for the first time, they became aware of people who did not agree or sympathize with their efforts to care for S₁. His prosthetic feeding device was considered to be unnatural and should therefore have been discontinued given the severity of his other injuries. Initially M and F were unaware of the true topic of discussion and were distressed to the point of being unable to sleep for several nights. It was not until several days later that it dawned on M that the program participants had been advocating "euthanasia". Reflecting on the participants and seeing her injured son, M realized that she would die for him.

Participation in the television program brought the topic of euthanasia into the open since M and F had never considered such an idea on their own. Since then they have repeatedly been brought face-to-face with this issue and find they are unable to ignore or disregard it. For example, F often ruminates on related issues such as the premise that dying from a terminal or degenerative illness is undignified and taking one's own life under certain circumstances is a

sign of strength. From his perspective, this way of thinking is "twisted logic". Both parents express a fear that the younger generation is more selfish and less caring toward humanity. F in particular sees this trend as dangerous given shrinking financial resources and the increase in disabled and disadvantaged persons who are dependent on social services. In his efforts to make sense of these ideas, F regards the talk-show experience as part of their education. They see themselves as having been duped into appearing on the show under false pretences. They are now more mindful and would be more cautious about sharing their situation with the media. Though S₂ was not involved with the television program, he finds himself questioning the motives of some who suggest that life is not always worth preserving.

The tragic occurrence of S₁'s accident has compromised the future orientation of individual family members and family life in general. M and F live each day as it comes with thoughts of the long-term future too uncertain to be contemplated. They pay little attention to the optimistic predictions made by some family members and acquaintances regarding S₁'s progress and dwell little on what might be. Only S₂ is making tentative plans for his future in terms of a career. He too has difficulty considering the idea of long-range plans, especially in terms of leaving the family home.

The question of S₁'s long-term care has not been fully addressed by the family and is experienced as very unsettling, especially for F. He admits that their most cherished preference would be for S₂ to care for his brother should they no longer be able to do so. While he is mindful of S₂'s entitlement to his own life, he nevertheless dreads the possible need to institutionalize S₁ should adequate contingency plans be unavailable. F feels caught between not wanting to burden or pressure S₂, while also being faced with the desperate worry over alternate care strategies should he and M be unable to continue

caring for S₁. When S₂ is questioned directly by F on how he feels about caring for his brother should the need arise, S₂ has difficulty articulating a response despite appearing calm. He shares that he really would not know what to do at this point in his life. F admits that prior to S₁'s accident he was better able to accept his children's growing independence and possible departure from home to begin their own life. Now he is not certain if he would be able to manage their leaving in a positive way. He actively encourages S₂ to live at home for as long as he wishes and "ideally forever". Knowing that S₂ still has his education to complete helps F feel more secure as it gives him more time to sort out his feelings. Personally, F finds the very notion of the future, the fact that things evolve and change, very difficult to contemplate and accept at this time.

M finds it difficult and almost impossible to even consider the future. Caring for S₁ is her only reality now and she is unable to see life beyond this. She believes her difficulty in contemplating the future is directly related to a profound fear of her own death. In envisioning the future, she inescapably sees herself as older and struggles with the fact that it is fruitless to worry about things that are impossible to control. But it is precisely for this reason that she does worry. She realizes that she has no control over what happens to F or S₂ and only limited control over S₁. What she fears most is the fact that she has little control over her own life. In talking she realizes that she has not even come close to addressing this issue. M also fears S₂'s departure from home. In jest, she states that she will not allow him to leave or marry. However, in a more serious vein, she says it is "common knowledge" that S₂ intends to remain in the family home even if he should marry. In response, S₂ acknowledges he is not yet ready to leave home. His central interest at this time rests solely on completing his educational program and proceeding to a more advanced

program. While he believes life will continue in the same vein, he also admits he really has not thought about the future.

As parents, M and F find themselves in an ironic situation where they believe it would be better if their child S_1 did not outlive them in contrast to the age-old parental concern of outliving one's children. Furthermore, F realizes that their ability to protect S_1 from an insensitive society is dependent on their own existence. He firmly believes that S_1 's survival is tied to their ability to remain united in their efforts to provide his physical and emotional care. Unless they are able to control their difficulties, S_1 will suffer, and the hope of helping him regain even a limited degree of physical and cognitive functioning will not be realized.

Caring for their son at home gives M and F tremendous comfort. They believe it is ironic to feel grateful that S_1 was involved in the type of accident where insurance compensation was provided, because it enables them to care for their son at home. Yet, they realize that having S_1 at home is a bittersweet experience. While they derive comfort and satisfaction from knowing that they are able to care for him personally, they are also painfully aware that the opportunity to do so has come at great cost. His normal development toward independent manhood has been cut short, and the care of his profound helplessness must extend to include the protection of his dignity and right to life.

Chapter VI

DISCUSSION OF RESULTS

Traumatic head injury has far reaching consequences. The stretching and shearing of neural fibres in the brain disrupts the individual's personal existence and also his or her interrelationships with family and the outside world. In the case of our research family, the metaphors of "brokenness" and "disconnection" extend from S₁'s body to his personal existence and in turn impact on the existential life-world of his family. This tragic event has not only torn S₁ away from his normal, everyday young adulthood, it has also led to an experiential disconnection of his family from their normal developmental life-course.

As human life is a meaningful, structured existence embedded within personal relations with others and the outside world, it was decided to use an existential-phenomenological research approach to investigate the deeper structural meaning of our research family's experience of living with a traumatically head-injured person. While the nature of S₁'s injuries and the experiential dislocation of his family meet the structural conformation of a tragic existence (Carrere, 1986), our findings further reveal the research family's experience of being "thrown" before the possibility of death (Heidegger, 1962/1926) and the effect of the near loss of one family member on the family as a whole.

The results of our phenomenological analysis show that, at least for our research family, living with a traumatically head-injured person alters the structure of family life at its very centre, in terms of its existential wholeness. The tragic "thrownness" of the accident precipitated a fundamental change in family life that led to family members feeling displaced from their familiar world, most notably the social and outside world. Their pre-accident existence in an

ordinary, taken-for-granted world was broken. At the same time, they found themselves confronted with an outside world that seemed impersonal, distant and at times overwhelming and threatening. Furthermore, the natural unfolding of life and the pull toward the future was prematurely cut short. Instead family members found themselves thrown into a life-world that demanded a more authentic response to their existence and in turn this gradually led to crystallization of the significance of family life. The prevailing demands of caring for S₁, protecting his right to life, and the need to maintain a sense of family became crucial in the face of an uncertain future.

Matrix of Dominant Themes

To further the understanding of what it was like for our research family to live with a traumatically head-injured person, we will present and discuss the matrix of themes which dominate and hold together the situated meaning structure of our research family's life-world following their eldest son's tragic accident. It is here at the thematic level that many of the foundational concepts described in Chapter II come to light as they manifest themselves within the context of our research family's life-world. To recapitulate, structure represents the dynamic configuration or matrix of interrelationships within the family constellation and between the family and the outside world. Structure is like the child's string game of "Cat in the Cradle", where the fingers represent family members and the string symbolically represents the dynamic interwovenness of the existential themes experienced by the participants. From playing this game as children, we know that while the fingers remain constant entities in and of themselves, they are able to alter the configuration of the connections between each other. At any given moment some relationships are closer together or further apart. At times we have indeed a cradle, a potential holding environment. As well, we know that if one or more fingers remain immobile

either because they are constrained by outside forces or because of internal immobility, the other fingers require greater agility and flexibility to successfully maintain the structure or create a new form. Should the more able fingers lack the resilience and elasticity to accommodate the inertia experienced by another finger, the structure becomes stuck and has the potential to become ossified. At times the string structure collapses, when the fingers slacken or come too close together, or the string is disconnected. Reconnecting the string requires outside intervention and, despite the ability and dexterity of the rejoining efforts, the knot remains a scar and testament to the brokenness. In effect the knot becomes a constituent, an entity, with full bearing on the structure itself.

The structural matrix of themes that emerged from our research family's experiential life-world is dominated by the themes of brokenness and disconnection and a call to care. We will see that the existential call to care surfaces as the dialectical response to the brokenness and disconnection experienced by the injured son and the family in general. Further interrelated themes, such as the family's restricted life-world, living with change and living in an altered time frame, describe the altered context the family found itself in. The themes of familial belongingness, living with loss and altered sensitivity to the world address the alterations in family members' attunement to the world while the disparity between inner and outer family life reflects the family's interrelationship with the outside world. What becomes apparent is the interplay between thematic constituents, how they invigorate each other and work to counterbalance each other. These dominant themes will be described and discussed in terms of their influence within the structural configuration of family life.

Brokenness and Disconnection

Brokenness and disconnection permeated personal and family life after the accident. The family found itself abruptly disconnected from its former pre-accident life-world and immersed within a medical world where the central focus of life was on their son's severe head injuries, coma and consequent impairments. Within the medical life-world, all attention was riveted on S₁ and his survival, and the family found itself relegated to the role of spectator. During the early weeks, family members' experience of personal agency was diminished but accepted as the family relied on the expertise and care provided by the health professionals to their son. They trusted the health professionals implicitly. However, the disconnection from their former sense of control and their inability to fully direct family life, especially how their son was cared for, soon surfaced and quickly became an issue to be rallied against. As M said, "Control, that's the word. You lose your control in a situation like that, you just have no control over anything".

At the beginning, facing their son's severely broken existence, the family was brought before the possibility of death. Hearing the attending physician say their son might not survive the night, shifted death from the realm of far-off possibility to that of a possible actuality. With their son's existence in peril, the family's own sense of wholeness and of identity was brought into question, and their primordial sense of trust in the durability of life was broken. During the early weeks of waiting and watching, the tenuous nature of their son's potential for recovery pervaded everyday life. Yet, the family remained hopeful that a certain degree of recovery would occur even if it was far in the future.

At the same time, the dialectical threat of losing an essential family member endured. In reaction to the threat of loss, i.e. the ultimate disconnection of their son from their family, came the urge to preserve and fortify their sense of

family wholeness. In the early days and months, efforts to maintain the foundation of their sense of family centred on working to restore and reinforce family connectedness and cohesiveness, commitment and belongingness. It was automatic, almost like a reflex reaction for them.

With attention focused on S₁'s survival and potential for recovery, the family's former social world of extended family, work colleagues, neighbours and acquaintances lost most of its significance, and the world of work receded into the background. As the parents invested all their energy into "being-with" S₁ at the hospital and searching to learn more about his condition, the break and sense of disconnection from the outside world increased and led to a growing estrangement from their former life-world and its natural ebb and flow.

With their return home, they intensified their efforts to reconnect and restore a sense of familial wholeness. Here in their home territory, they could at least control the coming and going of outsiders. Mindful of their own physical and emotional fatigue, all attention was directed onto S₁ and rebuilding their sense of family. Unfortunately, reconnecting their former relationships proved formidable, given their preoccupation with caring for S₁ and the lack of understanding demonstrated by other family members and acquaintances. The sense of disconnection and estrangement was far more pronounced for M and F. S₂, being less intimately related to his brother's ongoing need for care, was able to maintain most of his former activities and social connections (i.e. friends, summer employment and college program).

Restricted Life-World

Because the family was intensely focused on S₁'s survival and care, the family life-world was experienced as severely restricted. It had shrunk to the confines of the family home and only necessary outside responsibilities. Space and time were dramatically altered due to the family's centripetal focus on S₁'s

survival and recovery. The spatial world was initially confined to the hospital, in particular S₁'s room, and later to their own home. For the parents, life became highly structured. Beyond the routine of spending days and evenings at the hospital, and returning home to sleep, only unavoidable events or issues, such as urgent legal and insurance matters, or those issues pertaining to S₁'s long-term care, were attended to. S₂'s life-world was also altered. His former home-life temporarily vanished since his parents spent most of their waking time with S₁ or attending to related matters. Yet, of all the family members, he was the one person who was able to maintain a tentative connectedness with his former world of friends and rural neighbourhood while also visiting his brother on a weekly basis. For the family as a whole, S₁ and his existence became the geographic centre of their lives.

Familial freedom and autonomy were also severely compromised, especially during the hospital period. Life became regimented, in part because of their need to be with S₁ to reassure themselves of his existence and to offer him their support, but also to help provide a sense of structure when they felt life itself was out of control. However, living such a restricted existence led to an estrangement from the familiar environmental markers of normal living, e.g. work, recreational activities and even mundane household chores, which were essential to mediate the impersonalness of their situation.

The return to the family home restored some sense of their former family life and normalcy. Here they were in familiar territory and in close proximity to each other. Home life, however, now assumed a more traditional orientation in contrast to their pre-accident life with dual-career parents and active semi-independent young adults on the go. M remained home to provide S₁ with personal care, and to organize and oversee his comprehensive rehabilitation program while F resumed his former work responsibilities and S₂ was involved

in summer employment and later school. M further endeavoured to provide a sense of home and to be the "core" of the family.

Since the return from the hospital, family life remained centred on the home. Social life was virtually non-existent. There was no time for social activities, and relationships with others were restricted to a semi-artificial world of health professionals where personal sharing was limited to issues and concerns related to S₁'s well-being and his potential for recovery. M and F had little free time for personal interests or endeavours, or time alone together. Excursions away from home, whether necessary (medical appointments) or recreational (places of interest) were difficult and time-consuming, requiring extensive planning and preparation. All outings had to be arranged according to S₁'s feeding and sleeping schedules and had to be "universally accessible" to accommodate his equipment (e.g. wheelchair, parking for their specially modified vehicle). Although S₂ was engaged in college life, he had nevertheless lost the traditional carefree air of young adulthood.

During the early weeks and months of S₁'s hospitalization, the family's restricted life-world brought a dialectical reaction to the surface--an assertive stance against the encroachment on family life by external forces and an active reinforcement of family boundaries. It seemed that the greater the investment of energy in S₁'s well-being, the less significant the outer world became. And, as estrangement from the outside world increased, the safe inner world of the family took on greater importance. The family became a nest and haven where openness, responsiveness and acceptance of individual members and the family constellation became the underlying driving force. It seemed that the more threatened they felt, the harder they worked to protect S₁ and their sense of family. The more they perceived inadequacy in the external services provided for S₁, the harder they worked to rectify the situation, to

counterbalance the perceived omissions. The longer S₁ remained minimally responsive and treatment strategies seemed less than effective, the more they searched the external world for alternatives. In short, they endeavoured to defy the odds.

Living with Change

The accident plunged the family into a different life-world, a different existence (Van den Berg, 1972b). The suddenness of the occurrence and the gravity of the situation demanded an immediate response. However, the ultimate demand on family life was the challenge and willingness to live an altered existence. A deep-rooted flexibility seemed to allow the family to cope, to readjust and accommodate to a new life-order. Thus, they were able to accept the challenge of living in a dramatically altered life-space, in a constricted social environment and with compromised personal and family lives.

Since the accident, personal and family values had to be reprioritized. M and F willingly accepted this new yoke of responsibility. For the time being, they sacrificed their own personal development and future aspirations at great emotional and psychological cost, in order to devote time and energy to provide personalized care to their injured son and his brother. S₂ straddled two worlds, his family world with its realigned energies and focus, and his own personal world where overwhelming emotions often welled up dangerously near to his threshold of control.

Daily life was demanding, routinized and in many ways limited for the family. Spontaneity, the freedom to come and go, and time for personal interests were relinquished. In addition, the situation required a return to a time of increased sensitivity, responsiveness and attention to those in need. This required a parallel willingness to let go of things that were perceived as

irrelevant to their task at hand (e.g. socializing, recreational activities, and personal hobbies).

The family had to learn to be patient, to accept certain situations and to accept the fact that one cannot push or force healing. As well, they were called upon to respond to demanding situations as they arose and to use solid problem-solving strategies. There had to be a willingness to allow certain events to unfold at their own pace, especially in relation to S₁'s recovery. Aggravating and irksome details were often impossible to avoid and had to be addressed in the best way possible and in a timely fashion. While there was no respite from worry, a heightened sense of purpose evolved and with it a tentative restoration of normalcy and of familial wholeness.

Living in an Altered Time Frame

The advent of this tragic event arrested the normal flow of family life. In some ways family members were suspended in a time warp. In the early months life was measured simply in terms of medical routines and procedures, medical and professional appointments and consultations and markers of S₁'s improvement that were barely perceptible to the unschooled observer. External clock time had a bearing only if related to S₁'s care.

Following S₁'s return home, everyday life became highly structured, dictated by his sleep and feeding schedules and personal requirements. Family and marital activities had to be planned according to his needs which left minimal free time for either M or F. This highly structured life-style, however, afforded a degree of stability and predictability. It served as a foil for the tragic upheaval of their family life.

For the family, time became a paradox. On the one hand, days, weeks, years flowed into the next due to S₁'s limited progress and their rigid routine. On the other hand, many issues were experienced as urgent. At times, S₁'s

care required immediate attention and could not be postponed since there was the ongoing fear that tomorrow might not come.

The broader experience of time was also altered since the natural, future-orientation of life was prematurely cut short for S₁, tentatively compromised for S₂, and fearfully avoided by M and F. As well, the continuity of personal and family history was disconnected to the extent that the past was now relegated to distant memories.

The natural evolution of the family through the stages of the family life cycle was abruptly disrupted. The natural movement towards greater personal freedom and independence, a hiatus from intense familial responsibilities and the satisfaction of launching young adult offspring, was snatched from the parents. Instead, family life took on the characteristics of an earlier era with the added dimension of minimal opportunity for natural evolution.

At the same time, the outside world continued on with its own externally-directed chronological time-clock. Life moved with the passage of the work week, recreation time and family occasions. For the outside world there was always a tomorrow, there were always other opportunities. Difficulty arose out of the discrepancy between the family's experiential time clock and the outside world's time clock. The clocks lacked synchronicity and their coordination was artificially imposed. To the outside world, there was the assumption that after a certain length of time, there would be a return to a normalized life-style (i.e. engaging in outside activities). Yet, these external judgements of appropriate time frames never seemed to coincide with the family's experience.

Familial Belongingness

The family's disconnection from their former taken-for-granted existence and the near loss of their eldest son wrenched them from their sense of belonging in a safe and relatively predictable world. During the early days and

weeks, markers or cues of family and everyday life had little relevance. Given the gravity of their circumstances, the external world was perceived as either artificial and impersonal (e.g. hospital life) or as mundane and seemingly trivial (e.g. social world). Neither domain was acceptable. In response, cultivating family closeness, support, acceptance and cohesiveness seemed to be the only antidote in their efforts to restore and maintain some sense of belongingness. If they could not belong to the outside world and did not feel that they fit in, then they would do everything within their power to ensure a sense of belongingness within the family circle.

With S₁'s near loss, the family's sense of wholeness and therefore identity was put in jeopardy. In response, their natural, innate reaction was to join together and concentrate their efforts on preserving a sense of wholeness. Together, there was a sense of solidarity in the face of these threatening and overwhelming odds. The potential loss of S₁ permeated family life so that physical proximity became necessary to ensure a sense of belongingness (i.e. they needed concrete evidence). Even the faintest hint or sense of separation or being separated precipitated apprehension and anxiety. Consequently, all urgings from others for M and F to take a break or vacation from caring for S₁ were vehemently rejected. Given S₁'s extreme helplessness and inability to communicate with others, being away from him without "good" cause was not only inconceivable, it was intolerable. For S₂, being close to his family also became important. Following his brother's return home, he joined the family at dinner time on a regular basis unlike in the past when he was often out with friends. As well he reports there were many times when he preferred the company of his family to his friends.

In contrast to the special closeness of family life, the family often found themselves in a position where they felt misunderstood and unaccepted, not

only by their social world, but also by the medical-professional world they were forced to interact with. Given their limited interaction with the outside world, there was little opportunity to cultivate or reconnect friendships and develop a sense of belongingness in the outside world.

Living with Loss

The theme of loss figured strongly in all family members' lives. It was mentioned in both individual protocols and in the family interviews. For our research family, living with loss is living with an emptiness where previously there was fullness and a sense of wholeness. The near loss of S₁ cut across individual and family life. Individually, each family member lost his or her pre-accident relationship with S₁ and the potential maturing of that relationship. They also mourned S₁'s personal loss of an active life, free to grow and enjoy the challenges and joys of normal life events such as a career and eventually a family of his own.

For M and F, as parents of S₁, their former investment in personal interests was now rechannelled into ways of caring for S₁ to give him a quality of life and a sense of belonging within the family environment. Together they lost the time-space for sharing projects, ideas and dreams. Life was now task-oriented and focused on caring and providing for their sons. Despite their choice and willingness to redirect their energies, they deeply missed their former time together.

S₂ lost the opportunity for a relatively carefree young adulthood full of dreams and plans for the future. Instead, he now experienced his life-world as overly serious and full of sorrow. The near loss of his brother, coupled with other tragic events in his life, tore him away from a former emotional and psychological stability. Life now seemed unpredictable and threatening.

The near loss of S₁ threatened the family's former sense of wholeness, its sense of existential integrity. Over time, the persistence of S₁'s coma reinforced fears of loss such that the family's sense of identity also seemed threatened and in peril. When expected treatment strategies were not forthcoming, fear fuelled the apprehension that they would not be able to help their son recover some of his former ways of being. They also dreaded that their own lives would remain in a state of flux. To counteract their fears of permanent loss and instability, the family intensified its efforts--they tried to find health professionals to provide advanced treatment, and when that failed, they implemented techniques they had read to be effective (i.e. coma stimulation) on their own. Unfortunately these efforts tended to alienate hospital staff which lead to the family's greater sense of despair.

Altered Sensitivity to the World

Following their son and brother's accident, family members experienced a dramatic alteration to their general sensitivity to self, others and the outside world. Heidegger (1962/1926) refers to the emotional stance one has towards the world including other persons as attunement or mood. For the research family, life was now lived in terms of trying to counterbalance and compensate for what had been lost. To this end, they experienced an intensification of alertness and sensitivity to self, others and the world. They also lived with a fine-tuned vigilance to the appearance of new problems or a further deterioration of their present situation. Seen in a positive way, the heightened sensitivity allowed M and F to anticipate the needs of their sons and S₁ in particular, given his inability to talk or move on his own. In its extreme, it led to a heightened adversarial stance described by F as a feeling that they "had to fight for everything".

Early on, M and F realized their lives had changed forever and there was little hope of recapturing the past. However, rather than dwelling on how things were or could be, they vowed to focus on making the best of a difficult situation. Their focus on doing helped to ward off feelings of anxiety and a concomitant fear over a fragmentation or loss of their family as they had originally created it. Their commitment to care for their injured son and to nurture the family was facilitated by their underlying goal to preserve wholeness.

Their heightened sensitivity affected their emotions. Emotions, especially anger, seemed to lurk beneath the surface and were sometimes difficult to control. In the weeks and months following the accident, family members found themselves often expressing pent up feelings and concerns. In some ways they found that this was beneficial and even seemed to bring them closer together. They came to realize that anger was a legitimate response to frustration and most likely to emerge whenever they sensed a rejection or denial of appropriate services and treatment, or became aware of people who were insensitive to their plight. Unfortunately, the generalized presence of frustration and anger and the need to fight and stand up for the rights of their son also intensified their everyday concerns.

A growing appreciation for open communication and dialogue emerged following the accident. Within the family realm, sensitivity to others manifested itself in terms of increased openness and availability, with the parents intentionally seeking to help, understand and anticipate the needs of their sons. Communication with the outside world, however, remained guarded and at times rigid with little space for negotiation. Additionally, all family members became demanding and forthright, showing little forgiveness for those who transgressed their boundaries.

While there was a hypervigilance to all that pertained to family life, there also appeared to be a selective disregard for all that had little or no relevance to family life. This disregard extended to those persons who did not hold a similar philosophy or appreciation for the value of life or for their efforts to provide S₁ with a prosthetic environment. Given the lack of understanding they experienced from others, the family felt more or less compelled to disengage itself from society. If outsiders did not fit into their frame of reference and did not respond to their needs (i.e. lacked attunement to the family's plight), they were disregarded and often disparaged. There was a rigidity in the family's stance towards the outside world, including the sphere of professionals. Family members felt no obligation to comply with others unless it would benefit S₁ or their family as a whole. Yet sometimes, when reflecting, they wondered if their decision to take control of their son's care was the wisest decision.

Along with their increased sensitivity to self and others, there was a conscious effort to try to understand the neglect and sense of abandonment they experienced from some family members, close associates and outsiders. Despite their efforts to understand, the pain and sadness of the disconnection they felt persisted.

Disparity Between Inner and Outer Family Life

For the researcher, what was particularly evident was the push and pull that manifested itself within the family's lived-experience, and the disparity that arose between inner and outer family life. We saw that the traumatic head injury brought within view the possibility of loss of one family member and the potential disintegration of the family as they knew it. The threat of S₁'s loss signified a real possibility of breaking apart. We witnessed the family's near desperate efforts to protect and maintain a sense of familial wholeness. Close

proximity between family members helped ward off fears of breaking apart and losing what was formerly part of the whole.

Before the tragic accident, life for the most part, was lived naïvely and taken for granted. The threat of death broke their trust in life, i.e. that life would forever be there for them. In response, the family endeavoured to preserve and fortify what remained of their union, three whole family members and one severely injured one. They accomplished this through their emotional availability, their acceptance and their understanding of each other, and especially through their efforts to provide S₁ with a specialized treatment program responsive to his particular needs. Family commitment, cohesiveness and allegiance became the glue that reinforced and helped restabilize the experienced disequilibrium in their family life. In addition, the family's unremitting efforts to seek out and secure the most advanced in-home rehabilitation treatment for S₁ helped alleviate fears of further disintegration. S₁'s accident redirected the family's former life-stance, characterized by a general openness to life and experience, back onto the family itself, its everyday functioning and its welfare.

Because of this tragic event and mindful of the transitory nature of life, the family restructured their intersubjective life-world. Criteria for belonging to this family were reasserted, and family boundaries were redefined. Most importantly, they set a high standard for ethical conduct and understanding. In doing so, they placed demands on themselves regarding their commitment and effort to care for S₁. Furthermore, they endeavoured to leave no stone unturned in their search for equipment, services, supplies and treatment. If they were unable to procure what was needed, they would try to figure out ways to do it on their own.

Unfortunately, the high standard for inclusion often went beyond the available resources of the outside world that moved according to the parameters of everyday clock time and space. Invariably, others viewed the family's efforts to provide for their injured son as extreme and unreasonable. The underlying root of discord that arose between the family and the outside world, however, remained out of sight and beyond perception. What others in the outside world failed to recognize was the existential foundation of the family's response of caring in the face of their son's broken body and near broken existence, signifying the potential loss of the existential integrity and wholeness of family life.

The call to care

Care emerged as the most pervasive and foundational theme within the structural configuration of family life following the traumatic head injury of S₁. Care was the thread which wove its way through individual life-worlds as well as through the larger context of family life. Care was the broad attitudinal stance that transcended all facets of family life with its primary focus on the well-being and recovery of S₁ and secondly, on the family as a whole. This call to care arose from the ashes of S₁'s tragic helplessness and the loss of his freedom to create his own life. In effect, the call to care was a call to restore S₁'s sense of being and becoming no matter how limited his prognosis. Furthermore, care appeared to be the family's dialectical response to the brokenness and sense of disconnection they experienced due to the tragic accident and the consequent reactions of the outside world. Care was the call to authenticity (Heidegger, 1962), to the primacy of existence as being and becoming. Care also included recognizing the situatedness of being and becoming as life is lived within the constraints of one's circumstances. In this way, care became the authentic parental response to their son's loss of ability to direct his life and act upon his

world. To counteract his profound losses, his family endeavoured to provide a prosthetic home environment. Thus, the call to care provided the family, especially M and F with a purpose, and in so doing allowed them to rechannel and direct their energies toward a meaningful goal. They have been successful to a limited degree. Over time, their son has shown slight progress with increased alertness, vocalizations and minimal movement on his right side.

Caring for both their sons but especially for S₁ enabled M and F to regain a tentative sense of trust in life and in human nature. Through ministering and touching, a sense of reconnection emerged. The family's efforts to provide S₁ with a highly specialized treatment program also led to an increased sense of accomplishment and mastery over their difficult situation, as well as a new perception of the significance of what it meant to be a family. S₁ has not remained in what the hospital's discharge summary defined as a "persistent vegetative state". Despite his helplessness and the severe limitations of his ability to function, he communicated through his body and it is through his body that others understood him. His face and eyes belied nothing. We could say that for S₁, his existence was embodied in a literal sense--it was truly a "bodily" existence. And, despite his impairments, he is a person entitled to his own life, to respect and dignity.

The crisis in family life that resulted from S₁'s accident revealed the paradox of life and living. The tragic upheaval, the near loss of a family member, and the subsequent disconnection from their former everyday life-world precipitated efforts by family members to counteract and counterbalance the experienced instability and disequilibrium. From our phenomenological analysis of family members' written and verbal descriptions, we found that while the basic structural constituents of family life remained intact, it was the

structural configuration that was altered. The theme of care emerged as the "red thread" which made its way through the reconfigured family structure.

In summary, Figure 1 presents a visual depiction of the matrix of dominant themes that were revealed by the phenomenological analysis. The theme of brokenness and disconnection is shown to impact on a series of interrelated themes. Together these themes elicit a collective familial response in the form of an existential call to care. In turn, the existential theme of care is seen to pervade family life.

Insert Figure 1 here

Care as an Existential Response to Brokenness and Disconnection

The existential theme of care emerged as the central constituent in our research family's experiences of living with a traumatically head-injured person. By care, we do not mean simply caring for S₁'s body and well-being. Rather, our notion extends to the existential realm described by Heidegger (1962/1926) that is foundational to human existence. Care, in his existential-phenomenological philosophy, is the resolute nurturing of being and becoming. To care for another is the supreme call of human existence and experience. It is a call to experience life and the intersubjective realm to its fullest.

For our research family, the call to care provided family members with a sense of purpose and meaning. It helped them make sense of life and living following their son's tragic accident. Given S₁'s loss of active participation in his life, care became the family's all-out effort to honour and respect the personhood of their injured son, and to ensure that he would be able to "become" all that he was capable of becoming given his circumstances.

To further our understanding of care and its far-reaching influence on the

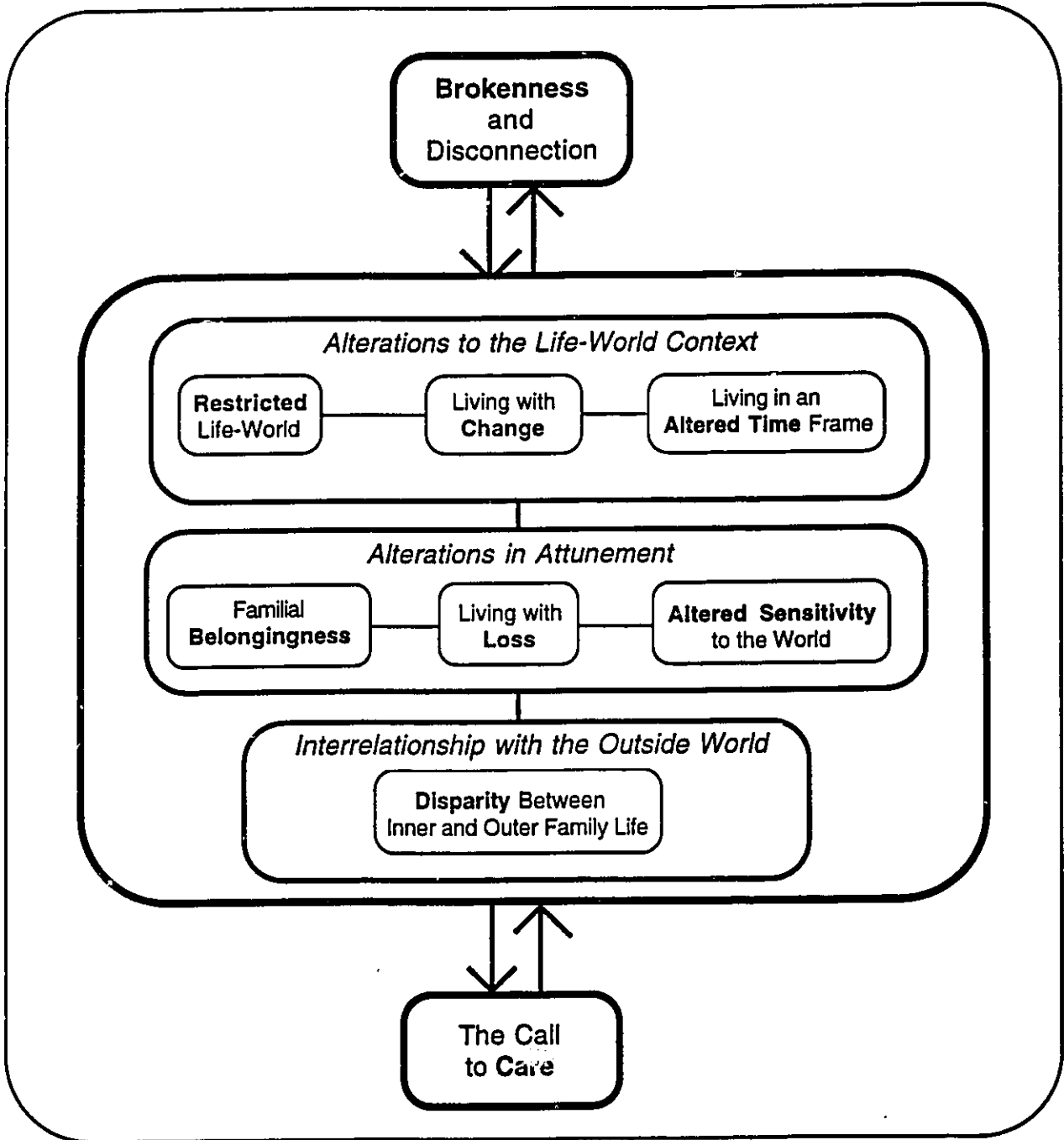


Figure 1. Matrix of Dominant Themes

reconfiguration of our research family's life-world, we turn to the theoretical and philosophical writings of Heidegger (1962/1926, 1985) where we learn of the inseparability of the existential theme of care and the themes of Beingness, authenticity, temporality and death. From Heidegger we learn that care is the underlying ontological structure and "penultimate" phenomenon of human existence and it is through care that individuals reveal themselves. As a "Being-in-the-world", each individual is unique and concerned about its own Being and existence which is at stake in everything it experiences and encounters. As a Being who exists over time, Dasein, the "there-being" of human existence with its underlying call to care, is grounded in the existential themes of existentiality, thrownness and fallenness. As existential Beings, individuals are drawn forward toward the future and therefore the ultimate destination of their existence, death. Thus, they are always seeking to discover what Heidegger refers to as their "ownmost potential for Being" (Heidegger, 1962/1926).

At the same time, individuals are inescapably rooted in their "thrownness", i.e. the situations they find themselves in and the existential ground from which all decisions and actions emerge. As Being-in-the-world, individuals are also "alongside" of that which is "ready-to-hand", as well as Others who dwell with them in their world. The ready-to-hand are the utensils and serviceable objects at one's disposal to help one realize one's full potential for Being. Being-in-the-world with Others is experienced either authentically or inauthentically, two sides of the same coin. The authentic encounter with others takes the form of concerned solicitude which is that stance and openness which helps the other realize his or her own potential for Being. Of course, individuals do not relate to everyone they meet or work with in a manner of authentic concern. It is not that they are indifferent to others, rather, most people have tasks to perform, responsibilities to keep, intentions to realize and projects and

concerns that preclude personal authentic relating with everyone encountered (Stack, 1969).

On the other hand, human beings are inclined to become caught up in the world of others, in the "theyness" of everyday living, and relying on external norms for direction. This absorption in "everydayness" was identified by Heidegger as "fallenness" or the falling away from authentic existence that, in turn, leads to estrangement from one's own sense of Being. When estranged from one's personal existential life-course, one experiences anxiety. Anxiety is the natural existential response to the fear of nothingness and going nowhere. In response, some individuals delve into the anonymity of the everyday world in order to avoid the call to authentic living, to facing the thrownness of life. For others, anxiety brings one face-to-face with the neglect and abandonment of the existential search to become one's full potential. In this way, anxiety individualizes personal existence as it reveals the call to conscience, to recognize the need to restore authentic existence and resume the forward quest toward greater openness in order to experience life as it is given.

"Resoluteness" represents the stance individuals take when they accept the call to conscience and make the existential choice of living life authentically versus remaining reconciled to living life as part of the crowd adhering to public rules. Resoluteness means "hearing the call of conscience", that is, understanding oneself in terms of one's existential guilt, i.e. one's running away from authentic existence. Resoluteness is not a psychological attitude or a habit. Rather, it is the existential stance of concerned listening to the call of conscience, to the call to care for the "Being" of Dasein. However, resoluteness does not mean living a life isolated from work or Others. It means, in reality, a concerned and respectful encounter with Others along with the givenness provided in daily living.

Time is the string that holds the structural constituents of existence together. In this way, temporality is the primordial unifying feature within the structure of care. Human existence is a temporal existence, that is, life is spread out in a three-dimensional extension--forward toward the future and backward toward the pastness of the thrown facticity of life, and conjoined in dynamic suspension by the presentness of the situation (Demske, 1970). The essence of temporality is its capacity to interweave the past, present and future as they manifest themselves in existential life as "having-been", "being-already" and "being-ahead-of". The primacy of temporality for Heidegger, however, lies in its future orientation. It is the future that awakens the present and pulls it forward, while also giving meaning and relevance to the past. Time is the underlying feature of care and the means by which human existence is revealed.

Death is the defining criteria of human existence according to Heidegger. It signifies the utter impossibility of existence. Without death, we are incomplete and unfinished. It is only in the finality of death that the fullness of a person's life comes into perspective. Consequently Dasein moves resolutely towards its completion. In this way, the individual is a Being-unto-death, Sein zum Tode. For Heidegger, individuals exist in a way that is authentically whole only when "thrown into death" (Heidegger, 1962/1926, p. 375). At the time of death the individual is thrown into its ownmost, distinctive possibility, a possibility that is unsurpassable and non-relational. In death, one stands alone and all relations with other beings cease to exist.

The finitude of death signifies the end or nullity of existence. In the "everyday" world, individuals flee from death and exist in a persistent, inauthentic flight that endeavours to conceal and avoid death. Yet it is this very phenomenon of evading death that demonstrates a recognition of the certainty of death on the level of existence, which is much deeper than external sensible

experience. In terms of existence, death is just as certain as Being-in-the-world, for death is "merely the reverse side of the same coin" (Demske, p. 280). For most of us, death is not conspicuous, a something that crosses our awareness. Rather, death is actively turned away from in favour of preoccupation in everyday tasks and idle talk. As an existential-ontological structure, death includes the elements of anticipation and its correlate acceptance. As an authentic Being-toward-death, the individual runs forward with an openness to what is given in life, which is an exact opposite of the flight from death that epitomizes inauthentic Being-towards-death as it runs away and surrenders to the fallenness of existence.

Acceptance of the potential for one's own death puts life into context. Without the active acceptance of death, the individual's certainty of death is held in abeyance and remains within the realm of imagination--temporally distant and personally inconsequential. Without the spectre of death, individuals cannot understand themselves in terms of the exclusivity of their own existence and their own personal significance. As well, they are more inclined to ignore the possibility of their own deaths and preoccupy themselves with what they think are the more immediate and pressing demands of everyday life.

Whether fleeing or moving toward death, individuals experience anxiety. In fleeing, however, they push aside thoughts and images of death, whereas when open toward or in the presence of the possibility of death, individuals are brought closer to the threatening impossibility of their own existence which, in turn, precipitates the fears of nothingness and going nowhere.

When faced with death, one is faced with the choice of furthering one's evasive strategies and sinking further into inauthenticity, or embracing the authentic call of conscience where life becomes a very different order from the limited concerns of everyday living. Life then becomes an ethical concern, with

a responsibility to live true to one's own convictions within the situatedness of life as it is given.

Being free-for-death, the goal of one's existence becomes apparent and one's life becomes simple. Once one grasps and accepts the reality of life, i.e. that one will die, one's life-path becomes clear and the endless searching out of possibilities becomes irrelevant. Instead, thrownness is lived in terms of the opportunities it provides to embrace life in all its ambiguity and inconsistencies and to realize one's inherent potentialities. Time becomes the road of life from birth to death. In inauthentic existence, individuals seek refuge in the distractions of the present through "busy-ness", and in doing so they try to avoid death. In this mode of existence, individuals readily succumb to the illusion that "there is always time left" (Demske, p. 52). They believe there is always a tomorrow with time left to complete tasks, personal projects, and time to be with others. In contrast, authentic Being-unto-death meets life in its thrownness and responds in a resolute and concerned manner.

When individuals are open to death and allow it to become all powerful in and of itself, they allow death to serve as the guiding light of their existence. In this way, they become "free for death" (Heidegger, 1962/1926, p. 436). This stance dialectically embeds them within a place of superior power, i.e. the power of finite freedom. In making such a choice, individuals take over the "powerlessness" of abandonment to the evasive, fleeing everyday world of the "they", and come to have greater openness and clearer vision for the possibilities, as well as the accidents, that are thrown their way.

If we accept that care is the underlying ontological structure of existence (i.e. it nurtures existence to its full completion) and death is an essential part of existence (i.e. it is the end point of Being), we may begin to appreciate the dynamic interplay between care and death. Care propels and spurs us toward

the full realization of our innate potentialities but always within the constraints of the world we are born into and find ourselves in each day. In doing so, care draws us toward the most extreme possibility of life, i.e. death. But with death, all possibility ends and life is extinguished. Consequently, polarization in either direction distorts and off-balances personal life. But living the inherent dialectical tension between both dimensions enables us to experience full and enriching lives.

S₁'s accident brought our research family before the very real possibility of death and his disconnection from their family. The anxiety that emerged, as he lay close to death during the first hours after the accident, was exacerbated by the possibility of the impossibility of S₁'s life. The possibility of losing S₁ completely or to a severely impaired way of life intensified the family's anxiety. In response, they accepted the call to conscience, the need to pull themselves away from their former everyday existence which, like for most other persons, was lived avoiding or denying the possibility of death. F said, "They were my kind of boys, they liked motorcycles, they liked that adrenalin rush, a little bit of risk-taking. I always liked that even though I was well aware of the dangers of some of the things. As long as they were properly prepared I was willing to take that, never, ever believing that either of them (sons) might get hurt."

At first, the family experienced a sense of blind faith in the situation they had so abruptly found themselves in. However, a different anxiety soon began to appear, an anxiety that forewarned the failure of hoped for help. To counteract the initial shock of the existential trauma, M and F conducted their own research to become knowledgeable about their son's condition, (e.g. what treatment strategies were recommended, and what they might expect in terms of progress). When the information they read did not seem to correspond with what they observed, more anxiety compounded their hospital experience. This

was related to their fear that methods of treatment proven helpful at other medical centres were not available to their son. It did not take much imagination to realize that because of S₁'s grave condition and the severity of his injuries, accessibility to such advanced and intensive rehabilitation was considered essential. In response, they endeavoured to provide their son with some of the recommended techniques and exercises. However, they soon realized that the hospital staff was less than accepting of their efforts. Tensions rose and dissatisfaction emerged as the family felt their situation becoming increasingly hopeless. It seemed as if the call to conscience--to recognizing pure and resolute authenticity--was their only solution.

By facing death when S₁ was so severely injured, a dialectical response to enhance life emerged within the existential structure of family life. Care was the honest, authentic response to the possibility of the "impossibility of existence" described by Heidegger (1962/1926). Unlike many families who live in "everyday" time and space, S₁'s family saw the face of finality. They almost lost S₁, and in losing him, their existential life would have been inextricably altered. Despite the family's reprieve from actual loss, the effect of the accident on the existential configuration of the family was profound. The call to care was a call to conscience, to recognize that a choice had to be made if S₁ and his well-being were to be restored. Given his very serious condition and severe limitations of voluntary responsiveness, it seemed as if all that remained was the fact that he was still alive. Accepting the call, M and F found themselves inextricably committed to caring for S₁'s existence. In seeing the possibility of his end, the essence of the meaning of his life for them suddenly became apparent. They resolved to sacrifice their own personal development in order to focus all their energies into helping him and restoring a quality of life befitting a beloved family member.

In M and F's resolve to live life authentically, that is, sensitive and responsive to the needs of all family members and S₁ in particular, the disparity with the outside world in its taken-for-granted existence became magnified and unavoidable. In response, they chose to reinforce family boundaries in order to more clearly define and protect what was "theirs" and what was not, what was included and accepted and what was excluded and rejected. Within the family circle, criteria for acceptance retained an inordinate degree of tolerance, acceptance and patience, while outside the circle, there was little tolerance for errors and omissions. Lack of trust in the outside world was exacerbated in the early months by negative and insensitive experiences with professionals at a time of extreme vulnerability and rawness of the existential wound. However, as the family became more resolute and demanding in their efforts to take control over their situation, they pulled back further from the outside world. Fortunately, over time and with great perseverance, a small but select team of trusted external service providers has slowly been retained. They were included in the family's interpersonal world and over time, a limited but guarded degree of trust in others was returning.

Looking closer at the phenomenon of existential care in the face of existential loss for our research family reveals a tenacity that defies normal everyday understanding. The question that emerges centres on the qualities inherent in and cultivated by this family that have allowed or compelled it to respond in this particular way and with this degree of resolve. The family interviews gave us a sense of the strong commitment to each other prior to S₁'s accident. A significant sense of belongingness and caring seems to have already been in place. In fact, M and F both shared their perceptions of being each other's best friend and being able to share even the most intimate details with each other. As well, a certain degree of flexibility was present as all family

members were moving to a greater degree of freedom and independence within a context of belongingness. The vulnerability of this family's life may inadvertently have been their ability and preference for their own family circle. While not isolated or alienated from the proximal world, we know they chose to live in a rural area that gave them greater privacy and independence from social rules. As well, most of their recreational and leisure activities were self-initiated and centred around the family's cottage that was even further removed from society's hustle and bustle. Because of their family cohesiveness, a strong social network had not been cultivated nor found to be necessary. However, at a time of intense existential uprooting and anguish over the tragic injury of S₁ and at a time of heightened vulnerability, the family's natural reaction to reground and reaffirm their sense of wholeness lacked outside support and confirmation. In Being-in-the-world, the world and especially the world of others is a crucial dimension of our lives. However, for our research family, they were significantly absent.

Dialogue with Previous Research Literature

Our survey of previous research in the literature review chapter substantiates the host of problems faced by survivors and their families following traumatic head injury. While interest in the plight of families is strong, research that focuses on alterations to family life have concentrated on individual or dyadic perspectives only and have included those survivors who, despite impairments, are still able to function in a limited fashion in their own home or in a rehabilitation setting (Karpman et al, 1986; Liberto, 1989; Oddy et al, 1978; Willer et al. 1990). For this reason, we believe that our existential-phenomenological study exploring the experiences of all family members provides a significantly richer portrait of family life following traumatic head injury. In addition, because of the severity of our survivor's head injury and his

inability to interact with his family except in a bodily manner, our research results offer a unique window on one family's experience of living with an extremely impaired head-injured person

In dialoguing with previous research literature, it becomes apparent that our research findings concur with many studies identifying difficulties and symptoms which arise as a result of traumatic head injury. However, our results move beyond a cataloguing of symptoms, difficulties and challenges and address the underlying structural changes which occur at the deeper existential level. In the following section we discuss the primary similarities and show where our research findings diverge and extend beyond previous research findings.

Mainstream research provides us with a broad and comprehensive picture of the functional (Karpman et al., 1986; Lezak, 1978; Oddy et al., 1978, 1980; Willer et al., 1990) and organizational changes (Blazyk, 1983; Hughes, 1990; Lewis, 1986; McCubbin and McCubbin, 1989; Rolland, 1987) to family life that may arise following traumatic head injury in one family member. While these studies provide a comprehensive picture of the problems and challenges faced by families living with head-injured persons, they fall short of addressing the deeper structural alterations which impact on family life in a more profound way.

The qualitative study conducted by Willer et al. (1990) into the concerns and challenges of mothers, siblings and young adult head-injured males highlighted the difficulties which emerged at the interface between families caring for head-injured persons and health care service specialists and providers. The tension described by our research family between themselves and health care specialists and providers concur with Willer's findings of mothers' difficulties accessing and securing appropriate services for their sons.

Additionally, our family's discovery of the need to "fight for everything" echoes Willer's research participants' observations of their need to be assertive with professionals and funding agencies in order to procure services for their sons.

Drawing on the writings of Merleau-Ponty (1942/1965, 1962) and Goldstein (1952) on the personal plight of head-injured individuals, we learned of the life-world alterations which arise from cognitive and perceptual impairments. As we saw, Goldstein addressed the impaired "abstract attitude" of traumatically head-injured persons and their concomitant reliance out of necessity on the "concrete attitude", which in turn precludes their ability to imagine, fantasize, deliberate and make decisions. Consequently, individuals find themselves trapped in the concrete here and now and unable to access the realm of the future unless it is directly at hand. Merleau-Ponty, on the other hand, showed how the impaired perceptual field affects the "intentional arc" which leads to impaired organizational and orientational structuring abilities of the person. Both writers attended to the alterations of the individual's life-world and their impaired existence within the intersubjective realm. Goldstein recommended a prosthetic environment to offset head-injured persons' predispositions toward a "catastrophic condition" which emerges whenever the underlying existential structure is sensed to be inadequate or unavailable. A prosthetic, externally structured environment provides boundaries, guideposts and grounding for head-injured individuals which in turn helps prevent the "catastrophic condition". In our research study, S₁'s parents tried to provide such a prosthetic environment for him. While the severity of his impairments precluded direct interaction with his surrounding environment, their efforts specifically attempted to counteract his inabilities. Consequently, they endeavoured to anticipate all his needs and desires in terms of physical comfort, sense of worth and belongingness in their family.

Liberto's (1989) phenomenological study of the experience of traumatic brain injury comes closest to our own study in that it is founded on phenomenological principles and uses a systematized phenomenological method (Giorgi, 1985). However, her primary research focus rests on the "dysfunctional communication loop" which often arises during difficult situations between head-injured persons and normally functioning others. Given that the head-injured participant in our study was unable to verbally communicate, it was not possible to compare research findings. Nevertheless, her study demonstrates the efficacy of phenomenological research as a viable and fruitful method for studying the alterations which arise to the intersubjective realm following traumatic head injury.

Lifton (1970) and Carrere's (1986) investigations of traumatic experience and tragedy respectively, expand our understanding of the larger context of living with trauma and tragedy over time. Their writings bring to light the disruptions that occur to the existential dimensions of time, space and place and the consequent alterations to subjective and intersubjective dimensions of personal life following a tragic or traumatic event. As such, their observations and research findings are particularly relevant to our study. Lifton, focusing on traumatic incidents revealed the foundational significance of death to traumatic experiences and its enduring presence over time. From his perspective, the structural configuration of life following a traumatic experience is interwoven with the face of death and death-images. With respect to our research family, S₁'s prolonged coma and minimal progress is surely reminiscent of death and the very near possibility of his family losing him. As well, Lifton's stage of psychic numbing aptly describes parental experiences during the first hours and weeks following their son's accident and may help explain the near

automatic routine they adopted in going to the hospital each day and returning home for sleeping and attending to urgent issues only.

While Carrere eloquently addresses and describes the altered life-world experienced in the context of a tragic occurrence, i.e. the displacement and sense of isolation from one's former social world and the alterations to the experience of time and space, we believe that our research findings concur but also go beyond Carrere's study by revealing the deeper implications of head injury to family life. The results of our research demonstrate that life-world alterations extend to the level of primordial existence. When a trauma or tragedy cuts to the core of existence, namely the possibility of non-existence, then structural alterations penetrate to the primal level of life and death, living and dying, being and not-being.

Heidegger's (1962/1926) theoretical writings on existence and death and the underlying existential-ontological structure of care appear to be particularly germane to our research family's experience of living with a traumatically head-injured person and provide the theoretical foundation on which to extend understanding of the plight of families following traumatic head injury. When individuals are faced with the close proximity of death, only care has the capacity to provide an antidote. However, to reaffirm existence, care must be resolute in its determination to foster life at all costs. When resolute, life moves beyond everyday trivialities and extraneous preoccupations. In nurturing life as it is given, care provides the impetus to help one realize innate potentialities and capabilities within the context of the ambiguity and arbitrariness of life.

When we are able to appreciate the radical alteration of individual and family life at its centre, that is, in terms of life and death, we may begin to comprehend our research family's near desperate efforts to care for their injured son and brother. In this case, care was far more than physical and functional. It

was rather, an existential caring which nurtured the very Being of S₁. In providing him with loving care, responsive to his physical needs as well as his emotional needs in terms of acceptance and trying to provide an interesting and comfortable environment, family members created a prosthetic existential life-world for S₁. Realizing his inability to interact with the world he now found himself in, they endeavoured to help him do so. They engaged in ongoing conversations, provided him with visual and aural stimulation and tried to provide an environment befitting a young adult male who has been tragically incapacitated. Lacking verbal language, S₁ communicated through his body and it is only through his body that others understood him. Here we bear witness to the primacy of Merleau-Ponty's (1962) concept of the body. We see that despite his inability to act by his own volition, his presence as an "embodied-Being-in-the-world" never faded.

Returning to the work of Lifton (1970) and Carrere (1986, 1989) who describe the evolutionary process of living with and transcending traumatic and tragic experiences, we learned that individuals are challenged to find personal meaning and significance in the traumatic or tragic event in order to be able to integrate and transcend their experiences. Finding meaning involves a struggle to make sense out of the event within the context of personal life. Moreover, a new configuration of personal significance with self and others must evolve so that the person no longer feels bereft or totally homeless within his or her social environment. From our results, we witness our research family's slow and tentative return to a social world which is still only minimally there for them. To do so they had to reconstruct a new social world according to a new set of criteria, i.e. who understands their plight and who is competent to provide what they need and how they need it. Furthermore, caring for their sons and S₁ in

particular provides M and F with a sense of purpose which serves as a first step on the road to finding meaning out of this tragic happening.

In accord with Mook's (1985, 1987) existential-phenomenological family therapy research, our study enabled us to uncover the nature of the underlying family structure which sustains and maintains the phenomenon under investigation. Mook establishes that if we attend only to the functional level of a phenomenon, i.e. symptoms and deficits, and even if we look at the interactive effects at this level, we are still limited to surface structures which merely make explicit the nature of the phenomenon in terms of functional attributes. Her research writings demonstrates that only when we penetrate the deeper existential level of lived-experience are we able to uncover the implicit meaning of the phenomenon we wish to investigate.

From our own research using an existential-phenomenological research approach, we were able to uncover a structural matrix of family life that addressed the multiplicity of structural alterations and provided us with a deeper understanding of family life following traumatic head injury. Our research results, derived from the written protocols and family interviews, enabled us to offer insights beyond previous research findings centred at functional and organizational levels of family life.

From our phenomenological results we see that the family's experienced lack of understanding, confirmation and empathy emerged as particularly prominent. Their sense of displacement, extended from their own social world of family, friends and neighbours to include hospital experts and personnel. From our research findings we can appreciate the source of the external world's lack of understanding. The external world, still tied to the "everydayness" of hospital procedures and responsibilities and the belief that life will go on, that there will always be time, moves in accord with clock time and is grounded

within an intact social structure. In contrast, families facing the possible loss of a loved one, and a very limited and guarded prognosis for recovery, live in an altered life-world. Thus the lack of congruence between the familial life-world and the outside ordinary world.

In addition, we see that the outside world lacked relevance for our research family. Their former frame of reference, tied to the everyday, ordinary world no longer had meaning for them. It became obvious that the structural shift in family life, with its focus on an authentic way of being and responding to the world and to their injured son in particular led to a rift between the family and others. From this perspective, it becomes understandable how the lack of interest and the inappropriate assumptions and opinions of others might be experienced as detrimental or even hostile to our research family, given that their primary way of being was directed solely to enhancing their son's quality of life. Only when the attitude and actions of others were in accord with their own, were they able to tolerate and accept the presence of others. We also see that their stalwartness, and their angry fighting stance is merely a manifestation of the resoluteness they share in their commitment to help their son. They know they cannot restore him to his former way of being, i.e. as a fully-functioning person. But they do know that as long as his spirit, his sense of self, even if altered, remains intact, they will do everything within their power to sustain, maintain and nurture this sense of self. This profound determination is a testament to the existential threat of loss they experienced.

Clinical Implications

Little research exists specifically addressing clinical interventions for families living with the after-effects of traumatic head injury. Zarski et al. (1987) suggest a structural systemic approach based on Minuchin's early work with families suffering from persistent psychosomatic difficulties. Ridley (1989)

presents a different perspective based on the transactional theory of stress and coping originally formulated by Lazarus (1984) which promotes "value restructuring". This helps the family reframe and redefine their experience as a potential for growth rather than being perceived in devastating terms. More recently, Miller (1993) points out that brain injury invariably stretches the adaptive capacity of the family system to its limit, often exacerbating existing family problems. He therefore suggests that more intensive family therapy approaches may be warranted when supportive and educative measures are insufficient.

The above approaches, which focus on the functional changes to the family structure, the utility of cognitive reframing when living with difficult situations, and the recognition of the need for formal family therapy when educative and supportive therapies are deemed inadequate provide practical and clinically useful suggestions. However, it seems apparent that if therapeutic attention looks primarily to functional and organizational changes to family life, it may be that the deeper and more urgent needs of families, who struggle with a crisis of existence which suddenly appears before them, are overlooked.

Before structural and functional changes may be addressed, the family who has encountered a traumatic head injury must, at least provisionally, come to terms with the question of existence and the fact that tomorrow was almost snatched from them. We do not question the validity of addressing structural and functional changes within the family or the need to foster cognitive reframing and reinterpretation of events. What we do suggest is that before clinicians move forward to help families cope with change, they first allow the family "to be". Families who struggle with the after effects of traumatic head injury need, first of all, a safe place where they can share their feelings and

experiences. They need to be accepted, which is translated into confirmation for who they are and how they are at that point in time. Clinicians need to "meet" families and offer them a space where it is "legitimate" to explore the despair and fears they are experiencing. By "meeting" we refer to the dialogal "place inbetween" (Friedman, 1985) where clinician and family members share a place of "trust, mutuality and partnership in a common situation" (p.5).

When the clinician is willing to meet and encounter the life-world of the family, unfettered by time or theoretical constraints, the family may be more willing to dialogue and explore existential fears and frustrations. When unmoored from familiar life-markers, when existence is in question, it is the reconnection with an understanding other which begs for attention. Friedman (1985), writing on the healing dialogue in psychotherapy, tells us that "the help of the therapist is not, in the first instance, a matter of finding the right words, still less techniques of communication. It is a matter of the dialogue of touchstones coming into being between one who cannot reach out and one who can." (p.217).

On reflection, it seems that when the researcher and concomitantly the clinician can be in a stance of openness that is receptive and unimposing, families will be more willing to share personal feelings and concerns. It is only from this starting point that therapeutic interventions should proceed. Miller (1993) points out that when interventions are introduced too early in the adjustment process, clinicians run the risk of catalyzing "a horde of unrealistic expectations and fantasies, denial and raw shame, guilt and catastrophic reactions on the part of the family" (p.90). He adds that family healing takes both time and skill.

Meeting families' therapeutic needs is formidable in the face of traumatic head injury and the limitations of our universal health care system. Shrinking

health dollars compromise the availability of psychological services. In response, clinicians often have time for "band-aid" treatment only, e.g. attending to structural changes or dealing symptomatically with depression. However, the cost to society for failing to "listen" to families and to at least "be with" them at the time of their deepest despair is dear. Healthy families require less adjunctive services in the long run. They are also better able to use available resources creatively and efficiently as they shoulder incredible burdens all within the context of familial love and caring.

Limitations of the Research Study

Research results surpassed the expectations of the researcher. It was truly a discovery-oriented process. Nevertheless, research limitations appeared in the areas of subject recruitment and data analysis.

Our original criteria for subject selection centred on intact family units including at least two siblings living in the home and with a head-injury survivor capable of participating in the family interviews. As well, time post injury was specified as from six months to two years. For our research project, three afternoons over a period of four weeks were required to complete the process.

Participant recruitment proved to be problematic. Repeated advertising through the local head injury association newsletter and personal recruitment at two out of town locations proved fruitless. Consequently, the director of physical medicine and rehabilitation at the local medical facility that provides intensive inpatient and outpatient rehabilitation services for head-injured persons was approached and provided with verbal and written descriptions of the research project and participant criteria. Through this personal contact, two relatively similar families, in terms of family composition, ages of siblings and time post-injury were recruited. In the original subject selection, the head-injured person in Family "A" was unable to actively participate in the research process due to

his severe impairments but the family composition and time post-injury met the research criteria. Following data collection, it was decided to exclude Family "B" since the earlier death of their youngest child as a result of a head injury sustained in a pedestrian-vehicle accident continued to have an effect on family life, especially for the parents. Additionally, family members were together only on weekends and holidays since the injured daughter was an inpatient at a head injury rehabilitation unit in a city two hours from her home and the other siblings attended university out of town.

In retrospect, it appears that our research criteria for inclusion in the study may have been too stringent, and this led to early difficulties securing appropriate volunteers. As well, given the high-stress and time-consuming demands of living with a head-injured person, many families do not have the time or energy to spare for research purposes. It is therefore recommended that recruitment criteria be adjusted to allow for greater flexibility and that multiple recruiting sources be approached in order to have access to a larger subject pool. As well, one must be clear on what the true focus of the research project is; in our case, it centred on what it is like to live with a head-injured person. A related topic might be the impact of a head injury in one family member on the family as a whole.

Because the consequences of traumatic head injury touch all facets of family life, there is much to tell. However, the expansiveness of the data leads to methodological difficulties. A research dilemma arose in terms of allowing the families to share their experiences with minimal direction from the researcher, versus being more focused on the research question with a potential to jeopardize the research project by distancing family members. Mindful of the families' frustrations with many professionals, it seemed patently important to retain a stance of openness and responsiveness to family

members' willingness to share of themselves. For our research families, this was the first opportunity where they were invited to honestly share with an outsider how this tragic event had affected their lives. There was a genuine concern that should the researcher try to intervene too much in the natural unfolding of family members' narratives, the family might sense that the researcher's agenda was more important than listening to family members' perceptions and experiences. Consequently, research parsimony was sacrificed in favour of the family's need to share their experience in a way that was comfortable to them.

In turn, data analysis of the family interviews was arduous and time-consuming in comparison to the written protocols which were more focused in nature. It is therefore suggested that greater proficiency with research interviewing might serve to facilitate a more concise and focused family interview while retaining the richness of the data and without the risk of distancing the family. This might be enhanced by more extensive pilot work where several families are interviewed specifically for the purpose of refining interviewing skills.

Further questions may be raised concerning the effect of the researcher's open and responsive stance to the family and the more pressing concern regarding the effectiveness of the researcher's efforts to "bracket" theoretical presuppositions and personal experience. Some may argue that a stance of openness with minimal direction may allow research participants to bypass areas which hold the potential to elicit discomfort. We contend that the efficacy of phenomenological research lies in its ability to reveal that which is concealed and to reveal the implicit along with the explicit. The ability to bracket or render non-influential what one knows about a phenomenon (Giorgi, 1988) is a demanding task and requires disciplined effort especially when the researcher

engages in a face-to-face dialogue with research participants. Consequently, one may legitimately question the extent to which a researcher is able to effectively bracket or set aside theoretical knowledge, assumptions and biases, especially when the researcher herself is the mother of a head-injured daughter and one is investigating the phenomenon of living with a head-injured person. Merleau-Ponty (1962/1926, p.xiv) reminds us that a complete phenomenological reduction is impossible. For this reason, phenomenological researchers engage in an ongoing process of bracketing and reflecting in order to identify and tease out times when personal biases and perspectives have seeped into the research process and consequently work to filter them out.

Implications for Further Research

The results of our research study demonstrated the viability of using an existential-phenomenological research approach to study the phenomenon of head injury and its impact on family living. Because the data was limited to one family's experience and to a family with a very seriously injured son, it was impossible to offer any general statements about the phenomenon of living with a head-injured person. What we are able to offer is a rich and deep account of this particular family's experience. Therefore, studying other families would provide an opportunity to explore similarities and variations (e.g. where the head-injured survivor is similarly injured, less severely injured or where the survivor is a young adult female. In particular, an indepth investigation of a family where the head-injured survivor is a young adult female comparably injured, could shed light on both the invariant features of structural changes to family life, as well as the extent to which gender influences familial responses following traumatic head injury. A follow-up study six to twelve months after the initial set of interviews would allow for an expanded temporal perspective on this phenomenon, to gain an understanding of the enduring features of living

with a head-injured person. In addition, an indepth investigation of a family where the head-injured survivor has resumed everyday activities would offer an opportunity to explore the impact of the inherent cognitive and psychosocial alterations following head injury and would allow for the exploration of alterations to the family's intersubjective realm related to the altered existence of the head-injured family member.

Methodologically, phenomenological family research is still in a formative stage. Further research would provide opportunities to refine interviewing styles and research procedures. Interviewing styles could be investigated to determine which methods are better able to elicit data that is more focused and less repetitive. Research methods could be explored to identify whether individual adjunctive interviews provide greater depth or if family interviews alone are sufficient and what role the written protocols provide.

Different research strategies could be undertaken to investigate the efficacy of each. A more traditional phenomenological research approach such as that suggested by Giorgi (1985), using written protocols followed by interviews for clarification, could provide a format for studying several families. From the research data it would be possible to explore commonalities between the families and arrive at a situated general structure underlying the phenomenon of what it is like to live with a traumatically head-injured person. An alternative method would be to follow individual written protocols with a conjoint family interview and then individual interviews focused specifically on the basic research question as demonstrated by Emmrys' (1993) recent phenomenological family study. In addition, family interviews could be followed by subsystem interviews, i.e. marital system, sibling system, in order to highlight generational and system similarities and differences. A wide range of options remain available when research holds to a discovery-oriented stance.

It would also be interesting to explore the number of interviews required to glean an adequate research data base (i.e. number and kind of interviews). Existential-phenomenological analysis is highly personal, time-consuming and demanding. There are no short cuts. It would seem, however, that greater experience would facilitate refinements to the research procedure and data analysis and therefore streamline the procedure to some extent to allow for the completion of larger research projects.

In conclusion, phenomenological family research offers a rich and rewarding research avenue for accessing and exploring the deeper structural configurations of family life. It provides a systematic research method that allows not only the identification of functional and organizational levels of family life, but also reveals a structural configuration integrating all facets and dimensions that contribute to a research family's life-world. As an interactive and dialogical process it is well tolerated by research participants. Furthermore, they seem to benefit from the opportunity to share their experiences and feelings in an open and receptive forum.

REFERENCES

- Barrett, W. (1962). Irrational man: A study in existential philosophy. Garden City, N.Y.: Anchor Books, Inc.
- Bell, D. (1990). Husserl. London: Routledge.
- Ben-Yishay, Y., Rattock, J., Lakin, P., Piasetsky, E., Ross, B., Silver, S., Zide, E. & Ezrachi, O. (1985). Neuropsychologic rehabilitation: Quest for a holistic approach. Seminars in Neurology, 5 (3), 252-259.
- Binswanger, L. (1963). Being-in-the-world: Selected papers of Ludwig Binswanger. (J. Needleman, Trans.). New York: Basic Books, Inc. Pub.
- Blazyk, S. (1983). Developmental crisis in adolescents following severe head injury. Social Work & Health Care, 8 (4), 55-67.
- Bleicher, J. (1980). Contemporary hermeneutics. Boston: Routledge & Kegan Paul.
- Brooks, D.N. (Ed.) (1984). Closed head injury. Oxford: Oxford University Press.
- Brooks, D. N. & McKinlay, W. (1983). Personality and behavioral change after severe blunt head injury: A relative's view. Journal of Neurology, Neurosurgery and Psychiatry, 46, 336-344.
- Carrere, R.A. (1986). Tragedy as a psychological experience: Psychoanalytic and phenomenological perspectives. Dissertation Abstracts International, 47,p. 1266B Order No. DA8609024
- Carrere, R.A. (1989). Psychology of tragedy: A phenomenological analysis. Journal of Phenomenological Psychology, 20 (1), 105-129.
- Cogswell, B.E. (1976). Conceptual model of family as a group: Family response to disability. In G. Albrecht (Ed.), The Sociology of physical disability and rehabilitation. Pittsburgh,PA: University of Pittsburgh Press.
- Colcleugh, S. (1991). The silent epidemic. disability Today, 1 (2), 38-39.

- Curry, A.E. (1967). Toward the phenomenological study of the family. Existential Psychiatry, Spring, 35-44.
- Dacey, R.G. Jr. & Winn, H.R. (1984). Controversies in the treatment of head injury. University of Washington Medicine, 10 (2), 7-11.
- Delbecq, A.L., Van den Ven, A.H. & Gustafson, D.H. (1975). Group techniques for program planning. Middleton, Wisconsin: Green Brier Press.
- Demske, J.M. (1970). Being, man and death: A key to Heidegger. Lexington: The University Press of Kentucky
- Dillon, M.C. (1990). Merleau-Ponty and the reversibility thesis. In H. Pietersma (Ed.). Merleau-Ponty: Critical essays. Washington, DC: Center for Advanced Research in Phenomenology and University Press of America.
- Dilthey, W. (1976). Selected Writings. (H.P. Rickman, Trans. & Ed.). Cambridge: Cambridge University Press.
- Dilthey, W. (1978). Dilthey's Philosophy of Existence. W. Kluback & M. Weinbaum, Trans.) Westport, Conn.: Greenwood Press Pub.
- Dilthey, W. (1989/1883). Introduction to the Human Sciences. Princeton, N.J.: Princeton University Press.
- Emmrys, C. (1993). Anorexia nervosa: A phenomenological exploration of family life. Unpublished doctoral dissertation, University of Ottawa, Ottawa.
- Epstein, N., Baldwin, L.M. & Bishop, D.S. (1983). The McMaster family assessment device. Journal of Marital and Family Therapy, 9 (2), 177-180.
- Epston, D. (1994). Extending the conversation. The Family Therapy Networker, 18 (6), 30-37, 62-63.
- Ermarth, M. (1978). Wilhelm Dilthey: The critique of historical reason. Chicago: University of Chicago Press.

- Fischer, W. (1974). On the phenomenological mode of researching "being anxious". Journal of Phenomenological Psychology, 4 (2), 405-423.
- Friedman, M. (1985). The healing dialogue of psychotherapy. New York: Jason Aronson.
- Gendlin, E.T. (1978-1979). Befindlichkeit: Heidegger & the philosophy of psychology. Review of Existential Psychology & Psychiatry, 26 (1,2 & 3), p.43-71.
- Giorgi, A. (1970). Psychology as a human science. New York: Harper & Row.
- Giorgi, A. (1975). An application of phenomenological method in psychology. In A. Giorgi, C. Fischer, & E. Murray (Eds.) Duquesne studies in phenomenological psychology: Vol 2 (pp. 82-103). Pittsburgh: Duquesne University Press.
- Giorgi, A. (1984). Towards a new paradigm for psychology. Studies in the Social Sciences, 23, p.9-28.
- Giorgi, A. (1985). Phenomenology and psychological research. Pittsburgh: Duquesne University Press.
- Giorgi, A. (1988). Validity and reliability from a phenomenological perspective. In W.J. Baker & L.P. Mos (Eds.), Recent trends in theoretical psychology (pp. 167-176). New York: Springer-Verlag.
- Glaser, B.G. & Strauss, A.L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago; Aldine.
- Goldstein, K. (1948). The organism: A wholistic approach to biology. New York: American Book Corp.
- Goldstein, K. (1952). The effects of brain damage on the personality. Psychiatry, 15, 245-260.
- Goldstein, K. (1971/1959). The smiling of the infant and the problem of understanding the 'other'. In. Gurwitsch, Haücek & Haudek (Eds.).

- Selected papers of Kurt Goldstein. The Hague: Marinus Nijhoff. (Original work published 1957)
- Goldstein, K. (1971/1957). Notes on the development of my concepts. In Gurwitsch, Haudek & Haudek (Eds.). Selected papers of Kurt Goldstein. The Hague: Martinus Nijhoff. (Original work published 1959)
- Halling, S. & Leiffer, M. (1991). The theory and practice of dialogal research. Journal of Phenomenological Psychology, 22 (1), 1-15.
- Heidegger, M. (1962/1926). Being and time. (J. Macquarrie & E. Robinson, Trans.). New York: Harper & Row, Ltd. (Original work published 1926)
- Heidegger, M. (1985). History of the concept of time. (T. Kisiel, Trans.). Bloomington: Indiana University Press.
- Herron, J. (1988). Validity in co-operative inquiry. In P. Reason (Ed.). Human inquiry: Developments in new paradigm research. London: Sage Pub.
- Hill, R. (1949). Families under stress. New York: Harper & Row.
- Horton, A.M. Jr. & Miller, W.G. (1984). Brain damage and rehabilitation. In C.J. Golder (Ed.). Current topics in rehabilitation psychology. Orlando: Grune & Stratton, Inc.
- Hughes, B.K. (1990). Parenting a child with traumatic brain injury. Springfield: Charles C. Thomas Pub.
- Husserl, E. (1967/1929). Cartesian meditations (D.Cairns, Trans.). The Hague: Martinus Nijhoff.(Original work published 1960)
- Husserl, E. (1970a). The crisis of European civilization (D.Carr, Trans.). Evanston: Northwestern University Press.
- Husserl, E. (1970b). The idea of phenomenology. The Hague: Martinus Nijhoff.
- Jacobson, M.S., Rubenstein, E.M., Bohanon, W.E., Sondheimer, D.L., Cicci, R., Toner, J., Gong, E. & Heald, F.P. (1986). Follow-up of adolescent trauma victims: A new model of care. Pediatrics, 77 (2), 236-241.

- Karlsson, G. 1993). Psychological qualitative research from a phenomenological perspective. Stockholm: Almqvist & Wiksell International
- Karpman, T., Wolfe, S. & Vargo, J.W. (1986). The psychological adjustment of adult clients and their parents following closed-head injury. Journal of Applied Rehabilitative Counseling, 17 (1), 28-33.
- Kaye, J. (1986). My mind is alive and well and fouling up the system: Existential-phenomenological considerations in family therapy. Journal of Family Therapy, 8, 183-204.
- Kockelmans, J.J. (1965). Martin Heidegger: A first introduction to his philosophy. Pittsburgh, Pa.: Duquesne University Press.
- Kockelmans, J.J. (1967). Phenomenology: The philosophy of Edmund Husserl & its interpretation. Boston: Anchor Books, Inc.
- Kockelmans, J.J. (1982-1983). On the function of psychology in Merleau-Ponty's early works. Review of Existential Psychology & Psychiatry, 18, p.119-142.
- Kockelmans, J.J. (1990). Heidegger's being & time. Washington, DC.: Center for Advanced Research in Phenomenology and University Press of America.
- Laing, R.D. & Esterson, A. (1970). Sanity, madness and the family. Baltimore: Penguin Books.
- Lewis, J.M. (1986). Family structure and stress. Family Process, 25, 235-247.
- Lezak, M. (1978). Living with the characterologically altered brain injured patient. Journal of Clinical Psychiatry, 39 (7), 592-598.
- Lezak, M. (1986). Psychological implications of traumatic brain damage for the patient's family. Rehabilitation Psychology, 31 (4), 241-250.
- Lezak, M. (1989). Assessment of psychosocial dysfunctions resulting from head trauma. In M. Lezak (Ed.), Assessment of the behavioural consequences

- of head trauma. frontiers of clinical neuroscience (Vol. 7), (pp. 113-143).
New York: Alan R. Liss, Inc.
- Liberto, M.M. (1989). A phenomenological study of the experience of traumatic brain injury. (Doctoral dissertation, Bryn Mawr College, 1989). UMI Dissertation Services 0622 DA.
- Lifton, R.J. (1979). The broken connection. New York: Simon & Shuster.
- Linge, F.R. (1988). Because I am involved in mankind. Quality, 1 (1), 1-6. St. Catharines, Ont.: Ontario Head Injury Association.
- Long, C., Gouvier, W.D. & Cole, J.C. (1984). A model of recovery for the total rehabilitation of individuals with head trauma. Journal of Rehabilitation, 50 (1), 39-45.
- Madison, G.B. (1981). The phenomenology of Merleau-Ponty. Athens, Ohio: Ohio University Press.
- Makkreel, R.A. (1977). Introduction. (In W. Diltthey, Descriptive psychology & historical understanding). The Hague: Martinus Nijhoff.
- Mauss-Clum, N. & Ryan, M. (1981). Brain injury and the family. Journal of Neurosurgical Nursing, 13 (4), 165-169.
- McCubbin, M. McCubbin, H. (1989). Theoretical orientation to family stress and coping. In. Figley, C. (Ed.). Treating stress in families. New York: Bruner/Mazel, Pub.
- McCubbin, H.I. & Patterson, J.M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. Marriage and Family Review, 6, 7-37.
- Merleau-Ponty, (1965/1942). The structure of behavior. (A.L. Fisher, Trans.). London: Methuen & Co, Ltd.
- Merleau-Ponty, M. (1964a). The primacy of perception. Northwestern University Press.

- Merleau-Ponty, M. (1964b). Signs. (R.C. McCleary, Trans.) Northwestern University Press.
- Merleau-Ponty, M. (1962/1945). The phenomenology of perception. (C. Smith, Trans.). London: Routledge & Kegan Paul.
- Miller, L. (1993). Psychotherapy of the brain-injured patient. New York: W.W. Norton & Co.
- Moehle, K.A., Rasmussen, J.L. & Fitzhugh-Bell, K.B. (1987). Neuropsychological theories and cognitive rehabilitation. In J.M. Williams & C.J. Long (Eds.), The rehabilitation of cognitive disabilities. New York: Plenum Press.
- Mook, B. (1985). Phenomenology, systems theory & family therapy. Journal of Phenomenological Psychology, 16 (1), 1-12.
- Mook, B. (1986a). Changing patterns of family life: A historical perspective. Psychotherapeia, 11 (1).
- Mook, B. (1986b). Towards a phenomenological approach in family research: Theoretical and methodological issues. Paper presented at the Fifth Annual Human Science Research Conference, San Fransisco, May, 1986.
- Mook, B. (1987). Phenomenology and family therapy. In F. van Zuren, F.J. Wertz & B. Mook (Eds.), Advances in qualitative psychology. Lisse: Swets & Zeitlinger.
- Mook, B. (1989). Intersubjectivity and narrative structure in family therapy: A foundational approach. The Humanistic Psychologist, 17 (3), 251-264.
- Moore, A.D., Stambrook, M., Peters, L.C. & Lubusko, A. (1991). Family coping and marital adjustment after traumatic brain injury. Journal of Head Trauma Rehabilitation, 6 (1), 83-89.
- Mueller-Vollmer, K. (Ed.). (1985). The hermeneutic reader. New York: Continuum Pub.Co.

- Oddy, M., Humphrey, M. & Uttley, D. (1978). Stresses upon the relatives of head-injured persons. British Journal of Psychiatry, 133, 507-513.
- Oddy, M. & Humphrey, M. (1980). Social recovery during the year following severe head injury. Journal of Neurology, Neurosurgery & Psychiatry, 43, 798-802.
- O'Hanlon, B. (1994). The third wave. The Family Therapy Networker, 18 (6), 18-29.
- Palmer, R.E. (1969). Hermeneutics. Evanston, Ill.:Northwestern University Press.
- Polkinghorne, D.E. (1989). Phenomenological research methods. In R.S. Valle & S. Halling (Eds.). Existential-phenomenological perspectives in psychology. New York: Plenum Press.
- Rickman, H.P. (1979). Wilhelm Dilthey: Pioneer of the human studies. Berkeley,CA.: University of California Press.
- Ridley, B. (1989). Family response to head injury: Denial or hope for the future. Social Science and Medicine, 29 (4), 555-561.
- Rolider, A. & Garner, S. (1992). Pharmacological and behavioral treatment of severe behavior disorders. Workshop at Royal Ottawa Hospital, Ottawa, ON, April, 1992, sponsored by Chedoke-McMaster Hospitals, Hamilton, ON.
- Romano, M.D. (1974). Family response to traumatic brain injury. Scandinavian Journal of Rehabilitation Medicine, 6, 1-4.
- Salner, M. (1986). Validity in human science research. Saybrook Review, 6, 107-130.
- Sartre, J.-P. (1956). Being and Nothingness. New York: Philosophical Library, Inc.

- Schutz, A. (1967). The phenomenology of the social world. New York: Northwestern University Press.
- Slaate, H.A. & Sendaydiego, H.(1984). The philosophy of Martin Heidegger. New York: University Press of America.
- Spiegelberg, H. (1965). The phenomenological movement (2nd ed.) Vol. 1. The Hague: Marinus Nijhoff.
- Stack, G.J. (1969). Concern in Keirkegaard & Heidegger. Philosophy Today, 13 (1/4), 26-35.
- Taylor, C. (1990). Embodied agency. In. H. Pietersma (Ed.), Merleau-Ponty: Critical essays (pp. 1-23). Washington: Center for Advanced Research in Phenomenology & University Press of America.
- Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, 38, 1161-1173.
- Valle, R.S., King, M. & Halling, S. (1989). An introduction to existential-phenomenological thought in psychology. In R.S. Valle & S. Halling (Eds.). Existential-phenomenological perspectives in psychology. New York: Plenum Press.
- Van den Berg, J.H. (1976). A different existence. Pittsburgh: Duquesne University Press.
- van Manen, M. (1990). Researching lived experience. London, ON: Althouse Press/University of Western Ontario.
- Vogenthaler, D.R. (1987). Rehabilitation after closed head injury: A primer. Journal of Rehabilitation, 53 (4), 15-21.
- von Eckartsberg, R. (1986). Life-world experiences. Washington, DC: University Press of America.

- Wertz, F. (1983). From "everyday" to psychological description: An analysis of the moments of a qualitative data analysis. Journal of Phenomenological Psychology, 14 (2), 197-241.
- Wertz, F. (1984). Procedures in phenomenological research and the question of validity. In. C.M. Aastoos (Ed.). Exploring the lived world: Readings in phenomenological psychology. Studies in the Social Sciences (Vol.13). Carrolton,GA: West Georgia College.
- Willer, B., Allen, K., Durnan, M.-C. & Ferry, A. (1990). Problems and coping strategies of mothers, siblings and young adult males with traumatic brain injury. Canadian Journal of Rehabilitation, 3 (3), 167-173.
- Wylie, M.S. (1994). Panning for gold. The Family Therapy Networker, 18 (6), 40-48.
- Zarski, J.J., Hall, D.E. & DePompei, R. (1987). Closed head injury patients: A family therapy approach to the rehabilitation process. The American Journal of Family Therapy, 15 (1), 62-68.

APPENDIX A

Family Members' Experiences of Living with a
Traumatically Head Injured PersonInformation

As part of our professional obligation in conducting research at the University of Ottawa, we are required by the University Ethics Committee to obtain the written consent of all participants involved. This is not to imply that the project in question necessarily involves a risk. The purpose is simply to ensure the privacy and the dignity of the participants involved as well as the confidentiality of the information which is shared by the individuals.

All participants have the right to refuse or to withdraw their participation from this study at any point by informing the primary investigator of their intent to do so. In addition, participants have the right to refuse to answer or discuss any question which makes them feel uncomfortable. Their refusal or withdrawal will have no impact on present or future services. Participants will sign two copies of this consent form, one to be held by the participant and one by the researcher.

The primary investigator, Mrs. Clark, will be available to discuss any questions or concerns should they arise during or as a result of participation in the research project. Furthermore, should any participant experience distress as a result of their participation in the research process, Mrs. Clark will be available to recommend and/or assist in the process of obtaining appropriate professional help should it be required.

A summary of the research findings will be available on request following the completion of the dissertation.

Consent

This is to acknowledge that I have read the above information and I give my full consent to serve as a participant in the research project entitled Family Members' Experiences of Living with a Head Injured Person, being conducted by E. Clark, M.A., a doctoral student and B. Mook, Ph.D., thesis supervisor, both affiliated with the School of Psychology at the University of Ottawa.

I understand that the project is principally concerned with exploring the qualitative dimensions of family life in families where one member has sustained a moderate to severe head injury, and that the project poses no known risk of physical or mental harm to me or my family.

My participation will consist of first responding to a family questionnaire pertaining to my views on family roles and functioning which will require approximately 15-20 minutes to complete. I understand that this questionnaire will help to determine subject suitability for the research project. Should I or my family be regarded as non-suitable subjects for this project and/or experience emotional distress as a result of my/our participation in the questionnaire process,

assistance and/or referral to the appropriate professional agency will be provided if required by the primary researcher, Mrs. Clark.

I understand that inclusion in the primary study involves giving a written or audiotaped reply to some research questions which will take approximately 30 minutes to complete and taking part in two family interviews of approximately one and a half hours each. The family interviews will be videotaped, and will be kept in a secure setting and only viewed or listened to for the purpose of this research project. When completed, the interviews will be transcribed for analysis. These written accounts may be used for research and/or publication purposes but only after all names and identifying references have been changed to protect my privacy. Once the tapes have been transcribed with no known trace of identity remaining, they will be erased.

As a subject, I reserve the right to withdraw my participation from the project at any time by informing the primary investigator of my intent to do so. My withdrawal will have no impact whatsoever on services I or my family might receive now or in the future. Should any questions or concerns arise during the project, Mrs. Clark will be available to discuss them to my satisfaction. Furthermore, should I or a family member experience distress as a result of my/our participation in the research project, Mrs. Clark will be available to recommend and/or assist in the process of obtaining appropriate professional help should it be required.

_____	Participant's _____
Signature	Name
_____	Address _____
Witness	_____

Parent/Legal Guardian	
_____	Researcher's _____
Date	Signature

Questions regarding the research project should be addressed to:

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APPENDIX B

Factual Information on Research Family

Early in January 1992, S₁ was involved as a passenger in a motor vehicle accident. At the time he was 23 years of age. The driver of the automobile failed a stop sign at a major highway and the automobile was hit by an oncoming transport truck. S₁ was admitted first to a local hospital for assessment and emergency attention and then air-lifted to a major trauma centre where he was admitted with multiple injuries including a left parietal skull fracture, pulmonary contusion and possible shoulder fracture and internal injuries. Appropriate medical resuscitation was carried out and an intra-cranial monitor was installed. Two days later, surgery was required to remove an epidural hematoma beneath the skull fracture due to his rapidly deteriorating condition. Approximately four months later, S₁ was discharged home at the request of his parents. His condition at the time was medically stable and described as "persistent vegetative state" due to severe brain damage and his comatose state which receded only intermittently.

In August 1993, approximately 20 months after the accident, the family was contacted by the primary researcher and agreed to participate in the research study. S₁ is the eldest of two sons. At the time of the interview he was 25 years old and his brother S₂ was 19 years old. His parents M and F, ages 43 and 48 years respectively, had been married for 26 years. At the time of the accident the family lived just outside a small town and within commuting distance of a large metropolitan area. F was employed full-time for almost 30 years with the cartographic division of the federal government. M had recently acquired a new position as a human resources assistant at a local provincially-funded mental health facility. Before, she had worked as an office manager for a local orthodontist for 10 years. S₁ was employed on a part-time basis at the

same mental health facility in the housekeeping department and had plans to return to his education in the near future. He had previously completed 1 year of a mechanical engineering program at a local community college. At the time of the accident S₂ had completed general level high school and was in the process of considering work and educational options.

At the time of the family interviews, F had resumed his work responsibilities while M was caring for S₁ at home on a full-time basis. S₂ was in his second year of study at a local community college. Since the accident, S₁ remains unable to talk or feed himself and is totally dependent on his parents for all his personal care and needs. He is able to move his right leg and arm slightly but lacks voluntary movement on a consistent basis. All family members are convinced that S₁ is aware to a limited extent of his surroundings and seems to understand to some degree what is being said to him. His parents indicate that on his better days he is able to blink his eyes in response to basic questions and seems to try to orient his head towards room activities, television, etc.

Addendum

Approximately one year after participation in the research study, the family was contacted for some factual information regarding S₁'s educational situation at the time of the accident. At that time M volunteered the following update on family life. Renovations had been completed to the family home. The family had hired a local nurse to care for S₁ one full day a week as well as three nights per week so that the parents may sleep in their own room. S₁ is a little more alert than the previous year and makes more guttural sounds. His parents have recently rented a motorized exercise machine to stimulate his limbs; and he is able, with coaching, to awkwardly manipulate a home-made mechanical device that allows him to operate the family's slide projector that

holds favourite family picture. F has reduced his work responsibilities to a four-day work week so that he may spend more time with his son and M is taking voice lessons and reports that her singing seems to have a soothing effect on S₁ when he is distressed or irritable. Recently, M and F took S₁ to Toronto for a weekend to visit a special exhibition displaying highly sophisticated adaptive devices for disabled persons. S₂ is presently enrolled in an advanced level program at the community college and has been fully employed over the summer months.

APPENDIX C

Analysis of Written Protocols and Transcribed Family InterviewsWritten Protocols of Question #1

Code: F is for Father, M is for Mother, S₁ is for eldest, injured son and S₂ is for younger son. All identifying features such as names of persons, facilities and towns or cities have been changed.

Protocol of FMeaning Units:

1. Before his son's accident, F and his wife were both working in [a major city in Eastern Ontario] and therefore they travelled daily together. This time spent together was often used to discuss family, future plans, finances, etc; all the things husbands and wives discuss that with household demands, they never had time for once home. These hours spent in the car were very special.

2. Since his son's accident and taking him home, F and his wife seem to lead separate lives in many ways. Although it has cemented their relationship in that they share a common goal in caring for their son, nonetheless the fact remains that he and his wife have lost much of the intimacy they once shared.

3. A large part of their summer and fall recreation was spending weekends at the family cottage. Due to the site of the cottage, this is no longer feasible. This cottage was part of F's life since he was 17 years old. It was here that he introduced his boys to the outdoor pursuits that were much a part of his life.

4. F has lost alot of his interest in the hunting which he had spent so much of his spare time pursuing, partly due to lack of free time but also because his son needs his companionship at home.

5. F cannot forget that his son is an adult male and unlike what many people try to do, he has not become a child again because he was head injured.

Transformed Units

1. Prior to F's son's accident, he and his wife used certain uninterrupted time to discuss and plan family-related issues. F considered this time to be very special

2. F sees his marital life as being cemented by their common shared goal of caring for their son but also as being separate and with a loss of their former mutual intimacy.

3. Prior to the accident, the family spent recreation time at the family cottage but this is no longer accessible due to its location. This cottage was significant to F in that it was part of his life since he was 17 and it is also where he introduced personally significant outdoor activities to his own sons.

4. F has lost interest in a favourite and heavily invested outdoor sport due to lack of time and the pull to provide his son with companionship at home.

5. Unlike many, F has not forgotten that his son is still an adult male and not a child again because of his injuries.

6. F's son was also a companion to him on many of these hunting trips.

7. Since their sons had reached that stage of independence, F and his wife planned to buy an airplane and spend their free time flying. It was a lifelong dream to have an airplane which was soon to be realized.

8. The majority of people do not understand that F cannot return to the way of life before because his son needs him for companionship and support. F's need to be with his son is stronger than ever.

9. Another aspect is his younger son. As much as part of being a parent is the worry of something tragic happening to one of your children, it is compounded in F's case because it happened to his older son and therefore the worry for the younger son is greatly heightened.

6. F and his son were often companions in his favourite sporting activity.

7. F and his wife had reached a stage in their family life where they were able to make future plans for themselves

8. F feels a lack of understanding from others concerning his inability to return to his former way of life due to his son's needs for his companionship and support and his heightened need to be with his son.

9. F worries more about his younger son since his common parental worries about a tragedy befalling a child has actually occurred to his elder son.

Protocol of M

(Personal Life)

Meaning Units:

1. The most devastating effect on M's life is the loss of her son. He had a wonderful sense of humour, kind heart and they shared a very close relationship. She mourns even more for what he has lost (getting married, having children, a career and enjoying life).

2. Another effect has been living constantly with the fear of becoming ill or disabled herself. Who would care for M's son?

3. This fear has been most evident when M and her husband go flying. She has only flown twice with him since her son's accident and on both occasions she was air-sick. This had never happened before and she has come to the realization that she is terrified of something going wrong, resulting in a crash.

Transformed Units

1. The overriding effect on M's life is loss; loss of her son and his unique qualities, their special relationship and especially witnessing him grow up and enjoy normal life events.

2. Fear of personal illness or disability and the loss of the ability to care for her son is with M constantly.

3. This fear is most evident when M away from her son and involved in their special hobby. Though she has only had the opportunity to go flying twice, she has nevertheless experienced air-sickness unlike the times prior to her son's accident. M attributes her air-sickness to her fear of an accident.

4. Once M realized the long-term effects of her son's injuries, she applied for a one year leave of absence. This was declined. M can't begin to tell how deeply hurt she was.

5. Another effect has been the feeling of isolation from family and friends. The consequences from a severe brain injury are so overwhelming that people tend to shy away from asking questions so M has reached a point where she refrains from making any comments about it.

6. M says it is interesting to note that other than her mother, her sister-in-law was the first to ask her what it was like to take care of her son and what professionals came in etc. (this was one and a half years after the accident).

7. Since M and her husband sleep in different shifts in order to position their son at night, they have lost much of the intimacy they once had.

8. M says she lives in a state of limbo. She worries about her son's health and whether or not she is doing all she can for him. M can't make any future plans because she doesn't know how far he will progress.

(Family Life)

Meaning Units:

1. Before her son's accident M and her husband had decided to move back into [the city] and buy a "hassle-free garden home". They were going to buy an airplane and spend their free time flying. This would also have facilitated their sons' going to college.

2. Once they understood the extent of their son's injuries, M and her husband decided to take him home where the environment would be familiar to him. The free time for flying is no longer since they have now doubled the size of their home, they have a lot more upkeep and housework to contend with.

4. M was denied her request for a leave of absence from her employment and this has hurt her beyond words.

5. M feels isolated from family and friends. She believes the severity of the injuries preclude others asking questions and she now refrains from commenting.

6. Only a couple of close family members have shown interest in how she experiences caring for her son.

7. The dramatic alteration to normal routines required by their son's personal care has impeded much of the M and her husband's former intimacy.

8. For M life is experienced in flux and is filled with worry over her caregiving competence. Future planning is foreclosed due to the uncertainty of her son's potential progress.

Transformed Units:

1. Prior to her son's accident, M and her husband had decided to change their living arrangements in order to be able to pursue a special retirement hobby and this would also have benefitted their sons' move to college.

2. Acknowledgement of the severity of their son's injuries led M and her husband to decide to bring him home to a familiar setting. Additional upkeep and housework preclude time for their special hobby.

3. Their son is very dependent on them for comfort and support and it is extremely difficult to leave him for any length of time.

4. M and her husband are constantly being told to go away on vacation or out to dinner etc. but her husband's vacation days are used up with appointments (medical for their son, lawyer and insurance people). M says there is no time for a vacation even if they wanted to which they haven't.

5. M and her husband travelled together everyday and did their shopping together etc. Her husband is now left alone to do these things. Also their retirement plans are cancelled because their son will need care the rest of his life.

6. M says she must end by saying that in spite of all she has written, this tragedy has brought them much closer, especially with their younger son. M thinks her younger son has realized how much they love and cherish him and his older brother and to what lengths they will go to help and protect them.

7. Also, by taking their son home they know he is receiving the best care available unlike chronic care facilities where he would have been all but ignored.

8. All in all, M feels they have made the best of a very tragic situation and will continue to hope and work towards a better future for all of them.

3. Their son's total dependence on them precludes M and her husband's absence for any length of time.

4. Continued urgings to take a break or vacation have been refused because formal vacation time has been used for necessary professional appointments and M and F lack any desire to do so.

5. Prior to the accident M and her husband shared commuting and related activities. Now he is left to do these on his own. They have cancelled their retirement plans in order to meet their son's ongoing need for care.

6. Despite the tragedy and its consequences, M believes it has brought the family closer together, especially with their younger son. M believes he understands the depth and extent of their parental love.

7. Caring for their son at home insures that he receives the best in personalized care.

8. Given the tragic circumstances, M feels they have made the best choices. They are committed to continue to strive for the betterment of all of them.

Protocol of S₂

Meaning Units:

1. The worst part of this situation is S₂'s feeling of helplessness although he has been able to go on with his life (school, going out with friends etc.). Its sad for S₂ to come home and see his brother so helpless, knowing that he'll never have the life he had and S₂ can't do anything about it.
2. S₂ says there's also a feeling of guilt in the sense that he seems to have so much and his brother has lost so much.
3. Since his brother would have been in college as he is, S₂ thinks they could have helped each other out.
4. S₂ and his brother were just reaching a point where they could speak civilly to each other and now that's gone.
5. (S₂ finds) It difficult to see his parents constantly worrying about his brother and to know how much their lives have changed.
6. S₂ knows his parents worry about him a lot more since the accident.
7. It is impossible to plan family trips now. They used to go to [southern US] to S₂'s uncle's every October for 2 weeks and as long as his brother continues the way he is they will never be able to go again.
8. S₂'s uncle has his own business, so it's not easy for him to come here. He has not been able to yet since his brother's accident and S₂ really misses him.
9. S₂ worries sometimes about what would happen to his brother if his parents were gone and if he could take care of him and how.

Transformed Units

1. Though he is resuming his own life, S₂ feels helpless in the face of his brother's plight.
2. S₂ feel guilt when he compares his life to his brother's situation.
3. S₂ fantasizes that they might have helped each other out while going to college together.
4. Their brotherly relationship was in the process of evolving to a more mature level of civility which is now gone.
5. S₂ is affected by his parents increased worry over his brother and the dramatic changes to their lives.
6. S₂ is aware of increased parental concern for him since his brother's accident.
7. Given his brother's situation S₂ believes special family trips, previously enjoyed on a yearly basis are no longer possible.
8. This precludes visits with a favourite relative which S₂ misses very much.
9. At times S₂ worries about his ability to carry on the family decision to care for his brother should something happen to his parents.

Written Protocols to Question #2

Protocol of F

Meaning Units:

1. Everyday F wakes up and sees his adult son reduced to a totally dependent person, totally defenceless and unable to communicate.

2. Yet F has to go to work where he cannot allow his own personal tragedy to affect his co-workers.

3. Indeed many people expect that F's life should have returned to normal.

4. Also, given the economic climate they live in, F is expected to be more productive than ever.

5. (F states that) unfortunately it is impossible to ever forget the tragedy of this situation.

6. (F says) it is amazing how many people believe that being at work will help him take his mind off this (his situation). (He states that) only people who have never gone through this type of tragedy could make such a trivial comment.

7. For F, work has become secondary, as well as his hobbies in view of this situation.

Transformed Units

1. Everyday upon awakening F is faced with the tragic reality of his adult son being reduced to a totally dependent and defenceless person unable to communicate.

2. Despite his situation F must go to work and guard that his personal tragedy does not intrude on his work and co-workers.

3. F believes that many people expect that by this time, his life should have returned to normal.

4. Being aware of the economic climate, F feels additional pressure to be even more productive at his place of work.

5. F feels that it is an impossibility to ever forget the tragedy in their family.

6. F is astounded by the number of people who presume that involvement in his work helps divert his attention from his tragic reality. In his opinion, only naive people could utter such a superficial comment.

7. F's career and other interests are now of secondary importance in light of the gravity of this situation.

Protocol of M

Meaning Units:

1. (M reports that) they have a van that is equipped with a lift and this enables them to take their son out for a drive or shopping, etc.

1. The family has a specially adapted vehicle which enables them to take their son places.

Transformed Units:

1. The family owns a specially adapted vehicle which enables them to convey their son places.

2. One day they decided to go to the Museum. At 6:30 am M gave her son his tube feeding. This took approximately 45 minutes.

3. Afterwards M gave her son a bath, washed his hair, did his mouth care and shaved him. This took about 1 hour. Following this she dressed him and lifted him out of bed and into his chair.

4. S₁'s father then wheeled him outside lifted his chair into the van and then he had to position all the safety belts around their son and then belt the chair to the tie-downs. This takes about half an hour.

5. While the father is with the son in the van, M makes sure she has packed all that they will need such as diapers, feed, water, medication, towel, etc.

6. They then leave for [the city] which is another hour. So far since her son's feeding, three and a half hours have gone by and they have arrived at the museum.

2. M describes a day they visit ed a local museum. The day's preparations began at dawn with M providing her son with his tube feeding.

3. Then M attended to her son's personal hygiene and dressing and finally she transferred him from his bed to his wheelchair.

4. S₁'s father then took over and wheeled his son to the van where he was loaded and his chair was secured for the trip.

5. While father secures their son and his chair for the road trip, M gathers the necessary equipment and provisions their son will require during their time away from home.

6. They embark on their journey into the city. M notes that it is mid-morning by the time they arrive at their destination.

2. M describes a trip to a local museum. The day begins at dawn when M begins her son's tube feeding and follows with his personal hygiene and dressing and concludes when she transfers him from his bed to his wheelchair.

3. Father takes over, loads and secures their son in his chair in the vehicle

4. While father secures their son in the vehicle M gathers the necessary provisions and equipment their son will require throughout the day.

5. They now embark on their journey into the city. It is mid morning by the time they arrive at their destination and they must now be mindful of the time required for the return journey and resettling their son in bed again.

7 (S adds that) they have to plan another one and a half hours to return home and put their son back to bed.

7. M adds that they must be mindful of the time required for the return journey and resettling their son once again in his bed.

8. (M states that) during their tour of the museum they have to plan it around their son's feedings

8. The museum tour must be organized in accord with her son's feeding schedule.

6. The tour must be organized in accord with their son's feeding schedule.

9. All in all, with all this it takes approximately 6 hours of care in order to spend perhaps 2 hours or 3 at the most touring the museum.

9. On reflection preparation and care takes twice as much time as actual touring of the museum.

7. On reflection preparation and care of their son take twice as much time as actual touring of the museum

10. (M states that) she must add that the benefits of taking their son out on an outing and the stimulation it provides him far outweigh the time it takes to get him there.

10. M feels that the benefits of the outing and the stimulation resulting from it far exceed the lengthy preparation time.

8. However, M feels the benefits of such an outing and the stimulation it provides far exceed the lengthy preparation time.

Protocol of S₂

Meaning Units:

1. (S₂ states that) his brother cannot speak but S knows he understands a lot of things going on around him.
2. When people come to visit most assume that since S₂'s brother cannot speak, he does not understand either and except for the fact that they say hello to him, after that they talk around him and very rarely will include him in the conversation.
3. S guesses people are uncomfortable with this and don't know what to say or do.
4. S₂ says sometimes he wishes they wouldn't bother to come at all.

Transformed Units:

1. Though his brother is unable to speak, S₂ knows that he is still able to understand much of what transpires around him.
2. S₂ remarks that most visitors assume that his brother's inability to speak means he is also unable to understand. Except for a perfunctory greeting most visitors exclude him from their conversations.
3. S attributes such behaviour to personal discomfort and ignorance with regard to appropriate behaviour.
4. The pain of witnessing this leads S₂ to sometimes wish visitors would not bother to come at all.

Family Interview 1

Code: M is Mother, F is Father, S₁ is eldest (injured) son, S₂ is younger son (D) and I is Interviewer.

As the camera is being set up the family is sitting around the table. M is on the camera's right closest to the wall, then F and then S₂. S₁ is on the camera's left and on the family's right. The family is not talking very much, they seem a little uneasy. M starts the conversation, F pays attention to her and S₂ tends to sit slouched over in his chair, often with his head down.

Meaning Units:

I: I guess the first thing I want to do is thank all of you because, I was really touched by the things you wrote. And I thought ... to maybe give me a sense of what things were like, I don't have a real sense of what your family was like before. To start, tell me a little bit about the kinds of things you did, how things were.

1. M reports that prior to the accident she was working full time at [a provincially funded psychiatric facility]. During that time her eldest son was also working there part-time as a housekeeping cleaner and her youngest son had just finished high school. Since he was not sure what to take he was taking a year off. Her husband was working for [the federal government] just down the road from where she worked and they travelled together quite alot.

2. M's youngest son was never home and her eldest son lived most of the time in the [nearby town] with his friends. She comments that at least S₁ worked with them and so he would come back and forth with them. She adds that their sons were basically on their own; at this point they were doing their own thing and her eldest son was 22 so he was rarely home except to eat and sleep.

3. M and her husband spent alot of their time flying as her husband had his licence and they used to go off flying and they would go out for dinner.

Transformed Units:

1. M describes the work status of each family member at the time of the accident. She worked at a local psychiatric facility, S₁ worked there also on a part-time basis in housekeeping, S₂ had recently completed high school but had yet to decide on a career or work goal and F worked for the federal government in close proximity to M's own place of employment which afforded them the opportunity to commute together.

2. Although both sons lived at home M and F saw little of them as they were basically independent.

3. M and F spent a significant amount of their time enjoying their special hobby (flying).

4. F says they were basically getting to the point where they had a lot of freedom in their lives and the boys used to look after themselves. [I: *They (boys) were kind of in the background.*] F agrees and adds that they came and went from home and that was fine, but the big thing was that they (parents) had gained an awful lot of freedom, they could stop and shop together. M adds that they could come home late. F adds that they could come home late and not have to worry.

5. M states that it has been a long time since they have been able to do that. Their youngest son was 16 (3 yr.. ago) when they started doing that.

6. M adds that actually they had started, no they had decided to move back to [the city] because they knew that their youngest son was going to be going to college and they thought they had been through a year of hell when their eldest son went to college because it was a real pain in the neck since they lived out there (in the country) and it was just paying for rent for an extra apartment, an extra grocery bill and all that kind of stuff. She states it was such a nuisance.

7. And besides M and her husband had thought, the hell with this, they have a big property, what's the point of taking care of it when they were never really home to do it. They thought, let's just get rid of it and move back to [the city] and get a town house, one of those hassle-free places.

8. F reports that it was usually in the summer time, most of their weekends were spent at the cottage so there was always a pull to recreational time. But they had their home to look after and the constant driving back and forth.

9. F says they were also thinking very seriously at that point that in not that many years they would be retired. And what did they want to do in their retirement. And this sort of precipitated their thinking about moving back to [the city], moving back so they could be close to the airport where they could park the airplane and they would have the freedom of coming and going.

4. M and F felt they had reached a stage in their family life where they had gained a considerable amount of freedom, feeling free to come and go as they wished while their sons were more in the background and were able to look after themselves.

5. M reflects that considerable time has passed since they began to enjoy their freedom.

6. They had already decided to return to Ottawa partially in anticipation of S₂'s need for city accommodation when ready to attend higher education in the near future. Doing it for S₁ had been emotionally very taxing for the family.

7. M and her husband had decided to streamline their living situation by selling their rural home which required considerable upkeep in favour of a relatively maintenance-free city residence.

8. F notes that they had an ongoing pull toward recreational activities. Summer weekends were largely spent at their recreational residence which entailed extensive driving.

9. F states that they were also in the process of contemplating his approaching retirement and how they would spend this time. This precipitated consideration of a residential move to the city to facilitate easy access to his chosen retirement hobby (flying).

10. M states that their youngest son was miserable thinking about this [I: *He didn't want to leave?*] and he adds that he didn't like the city, it was too big. M says that he had never lived in the city as they had moved out to the country when he was not quite 2 and this was all he had ever known. She says they took that into consideration but then they realized that even at that, if he was going to college he would still be away from his friends. But they thought he could still see them on weekends as its not like they lived 200 miles away. They were only 35 km.

11. [I: *So, you were just, still planning this and thinking about this*] M states that they had decided they were going to move. [I: *Was that going to be like within a year, or 2 years or 5 years or something like that?*] M replied that they had basically decided that as soon as they could sell their home they were going to do something. They knew that it wasn't going to sell quickly because the economy is so bad. It was a case of what they were going to do and they were going to wait until the spring and do some painting and fix up some stuff and then put the house on the market.

12. M says that S₁ then had his accident. [I: *That was in January?*] She says it was in January so it (the move) would have been that summer and they had hoped that the house would have sold inside a year.

13. [I : *But in a way it sounds to me as if you had the plan for the future, you were looking towards the future.*] F says this was for certain, [I: *and you know if it happened in 3 months or 6 months or a year.*] they had no concrete time limits or anything like that. They were thinking about the future and what they were going to do, what they wanted to do.

10. M reports that S₂ was distressed over their pending decision to move to the city which S₂ substantiates. M adds that he lacked experience with city living having moved to their present residence when he was a toddler. M acknowledges they took this into consideration but then realized S₂'s changing circumstances in that he and his friends were all in the process of moving onto higher education. They believed S₂ could still have access to his friends in the country given the proximity of their intended residence.

11. I reflects that they were still in the process of contemplating this change and wonders about the time frame. M asserts that the decision had been made and in consideration with the depressed housing market they planned to complete some refurbishment and then proceed with sale plans.

12. M states they anticipated a sale within a year but S₁ was then involved in his accident.

13. I says it sounds as if they were focusing on and planning their future. F agrees and adds that their plans were clear but open ended and without time limits.

14. [I: *How about for you S₂? How was that, how were things for you?*] S₂ says they were kind of sickening and he was sick and fed up. F asks if this was because he didn't really know what he was going to do. S₂ says he didn't know where he was going and then that he wasn't doing anything. [I: *So you didn't have any plans or there was nothing on the horizon that really captured your fancy?*] He says no.

15. [I: *And then you heard that your mom and dad were thinking about (moving)].* S₂ states he didn't like that idea [I: *So as the plans seemed to get a little bit more specific did you get more uneasy?*] because he doesn't seem to like to go out in his backyard and have the neighbours see him. [I: *Yeah, well there's sort of more opportunity to do what you want to do, you don't have to go by social rules all the time.*] S₂ says "exactly".

16. [I: *How was it for S₁ at the time?*] M reports that S₁ loved it there also. When they mentioned moving to [the city] he told them he could understand their point but he thought he might stay in [the nearby town]. M asked what the point would be, in that if he stayed in the [nearby town] then it would be just the same problem.

17. But M thinks S₁ basically had reached a point once he started working at the [psychiatric hospital] where his whole outlook was changed and he was realizing he was going to work for at least another year and she thinks he would have been more content then to move back to [the city].

18. S₁ and his girlfriend were pretty well ready to break off and M thinks the tie was beginning to be severed, on S₁'s part only but it was happening so she thinks he would have been ready to go.

19. I: *But he was, it seems, sounds as if S₁ was a little bit more open to the fact that you were thinking about future plans.*

14. (When asked how things were for him) S₂ states he was ill with distress. (When questioned by F if this was connected to lack of goal orientation) S₂ admits he lacked life direction and felt caught in a pervasive inactivity. On questioning, S₂ agrees this was in turn related to lack of future plans or interests.

15. When questioned about his parents plans to change residences S₂ states he did not relish the idea in that he preferred the greater privacy and freedom of movement and social rules afforded by their present residence.

16. M states that S₁ also preferred their present residence but had told her before the accident that while he could appreciate their desire to move he might consider remaining in the country. M felt that the original accommodation problem would continue to exist.

17. M believes that since employed, S₁'s perspective had changed and realizing the prospect of the need for continued employment, she expected he might be more amenable to their pending residential change.

18. M adds that S₁'s love relationship was on the verge of dissolution. At least on his side the tie was being severed and this may have further contributed to his readiness to move to the city with them.

19. I observes that S₁ seemed more open and receptive to his parents' future-oriented planning.

20. (In a louder voice) M asks if I would like to know what S₁'s exact words were. He told her in the car one night while they were driving home from town (S₁ starts to snort loudly) M told him that she and his dad were thinking seriously of moving back to [the city]. Her son turned to her and said "Mom, you and dad have been our parents for all these years and you've been the best parents and you deserve to do what you want to do." M emphasizes that that is what he said. [I: *Its really something isn't it?*]

21. M comments that S₁ was 5 years older than their youngest son. [I: *There's a big difference, isn't there?*] M agrees. [I: *Like he was really becoming more of his own (person)*]. M agrees and adds that for S₂, they really stewed long and hard over this because they knew the heartache this would cause him.

22. M says they sort of had to balance the two, what was going to be worse for S₂ and what would be better for them. And they kind of had to do a compromise between the two.

23. M says that they told S₂ that he could always have the car and he could get to [the nearby town] on the weekends and his friends could come down.

24. M thought that S₂ might come around because all his friends were going to be scattered too. They were all going to college and stuff but none of them did. S₂ confirms this.

25. M speaking louder says to her S₂ "You were the only shining light out there, my dear".

26. F says of course he too prefers the country also and it is only because of the flying that he would go back (to the city) and M adds the convenience too.

27. M then adds that (the flying) was the only thing they missed because living there is fabulous, peaceful, quiet and pretty.

20. M recounts that in response to her sharing their serious contemplation of a residence change with S₁, he affirmed their outstanding parental involvement and to their right to make their own future-oriented plans.

21. M states that the age difference between S₁ and S₂ plays a definite role in their varied reactions. I states that it seemed that S₁ was becoming more independent and M agrees. M shares that they agonized over their pending decision to move in light of the anguish this would cause S₂.

22. M adds they strove to balance both sets of concerns and ended with a compromise.

23. M says they indicated to S₂ their willingness to provide him with transport and to enable him to continue his friendships in the country.

24. M expected S₂ would eventually agree given that all his friends were ready to pursue higher education. In reality most stayed in the area.

25. M endearingly states that S₂ was "the only shining light" among them.

26. F says he can relate to S₂ in that he too prefers rural living and that it is only his special hobby (flying) that impels him to consider a residential change.

27. M states that rural living has many significantly appealing features (peaceful and bucolic).

28. M tells that one day she went to [a new housing development] and almost threw up. Her husband was not with her, her mother was. She reports that it was not built up, only the homes were built. They were nice but she could feel the claustrophobia and she thought she would not like living there. In a louder voice she says they will not live there.

29. [I: *Did you do things together as a family? I know S₂ mentioned about going on trips, that he has a favourite uncle in the southern US So did you go away, did you do, still do certain things together, it sounds like*] F reports that his sons occasionally went hunting with him which was a big part of his life. And that is where the trips to [the southern US] come in. For his wife they were trips for visiting her brother but for him it was for the deer hunting.

30. F says they did that (going to the southern US) and going to the cottage was also a focal point for him. [I: *That's a family cottage?*] This is a family cottage that his parents bought when he was 17. [I: *Where is it?*] It is about 45 minutes away on the other side of a neighbouring town. It was a big part of his life but not so much for his sons but they certainly went there for the waterskiing and some fishing and things like that. F adds that his sons had reached the point where they had their own interests.

31. F states that the sons were certainly welcome to go with the parents.

28. When visiting a new housing development M almost became ill. Despite realizing the area was as yet unfinished and the homes nice, she experienced claustrophobia and vehemently decided this area was no for them.

29. I asks if they did things together as a family and refers to an annual family trip to visit a special relative which S₂ had described. F replies that S₁ and S₂ occasionally accompanied him on his favourite sporting activity (hunting) and point out how as a family they combined this sporting interest with family visiting (to M's brother).

30. As well the family went to their recreational residence which had been in F's family since his teen years. This place figured more significantly in his life than in his sons' lives yet both enjoyed it for pleasure sports. F adds that his sons were at a stage where they were establishing their own interests.

31. According to F S₁ and S₂ were always welcome to accompany their parents.

32. [I: *So there weren't those hassles if you wanted them to go with you still or that you were concerned about where they were or?*] F says that because the boys were independent at that point they did pretty well what they wanted to do and there weren't any hassles about wanting them to go places with their parents. [I: *Sounds to me like things were fairly comfortable though.*] All agree. M asks S₂ if they was a yes or a no to which he says yes. F states that they never had a problem with the kids or fight with them to do things with the family. And as they got older and more independent, there was a natural evolution and there was never any problem for them.

33. M adds that they never forced the sons, they never said "Look, grandma wants to see you, you have to be there".

34. M adds that at that age (when children are older) they don't follow and they do their own thing and she can easily relate that to when she was that age. And everybody realizes that.

35. [I: *What about, um in terms of friends and social life? Do you have a large circle of friends? Or did you go out very much? Do you do alot of things with friends or outside of your own personal family?* All say no. F says they did not do very much outside their own personal family.

36. M adds only up at their cottage and that they see her uncle twice a year and one of those times is at Christmas.

37. M states that the thing is that they live 40 miles away and the winter time is a drag and when they work all day, the last thing they felt like doing was seeing (others). She says she would never drive back into [the city] just to say "Oh hi Mom and Dad, how are you".

38. M says that that may sound kind of mean but that was the way it was and she doesn't regret it. But she speaks for herself but she is sure it was the same (for the other family members).

32. There were no (parental) arguments with regard to family-related activities since their sons' growing independence was accepted as part of the natural maturational process.

33. M adds that S₁ and S₂ were never pressured to visit extended family.

34. According to M they all accepted the entitlement of older children to greater autonomy and she is readily able to relate that to her own experiences..

35. When asked if they had a large circle of friends or went out very much, F reports that most activities involved their own personal family.

36. M adds that socializing was mainly at their recreational residence and occasionally during holidays.

37. M states that socializing is a low priority given distance, work and weather factors. They would never return to the city for the sole purpose of visiting.

38. Speaking for herself, M believes her feelings are congruent with other family members. She suspects her statement may be considered unkind but she candidly states that that was their reality.

39. As for herself, M worked with people all day long and as much as she loved working in personnel she was dealing with people all day long and when she came home at night she didn't want to hear the phone first of all.

40. M says that their friends were also working so they were all in the same boat. They never saw each other more than they saw them.

41. M mentions that S₂ was all over the place. [I: *That's a good sign, the way its supposed to be.*]

TECHNICAL BREAK

42. [I: *OK, thanks for that little break. Now, I want to ask you about your reaction to the accident, the one thing is the night of ... but sort of in the right after, I terms of yourself and how the family moved or whatever ...*]

43. M says she was the person who answered the phone. She tells how it happened. S₂ was out and S₁ had met the kid who was the driver. This person had called S₁ that day and wanted him to go over to his place. S₁ had said, "No, I don't feel like it, I have to work tomorrow".

44. M guesses that the kid's parents were away and he was really lonely and he had said that another boy was going to be there and he'd pick up S₁ as he would like to see their place (he lived just down the road).

45. M says she could tell S₁ did not want to go but he felt he didn't want to hurt the guy's feelings and so he said "fine" and off they went.

46. They left around 25 after 7 and it was 20 after 9 when she got the phone call. All the doctor said to her was "Is there an F or M "A" there?" M said that it was M "A" speaking and the doctor asked if she had a son S₁ and when she said yes he said he had been in a serious accident and that he had stabilized him and he was being airlifted to [the city].

39. For M, given that she worked in a personnel position which she thoroughly enjoyed, she nevertheless had no desire for contact with people after work hours.

40. Given the similar circumstances of their friends (in the city), diminished visiting was common.

41. M states that S₂ was very active socially.

42. I asks for a description of their reactions to the accident and their experiences during the early days.

43. M received the news first (by phone). She describes how S₂ was out with friends and S₁ had been invited by the driver of the accident vehicle to visit him at his home and that S₁ had declined due to a work commitment the next day.

44. M surmised that the driver was quite lonely due to being home alone and had invited S₁ and another person over. He offered to pick S₁ up, on the pretense of wanting to see their home.

45. M believe S₁ agreed to visit so as to avoid hurting the driver's feelings.

46. The call from the hospital arrived approximately two hours later requesting either parent. When M identified herself to the medical expert, he asked if she had a son named S₁, whom he then identified as having been involved in a serious accident, was being stabilized and airlifted to a trauma hospital in the city.

47. M said she said "You're joking" because they were forever calling because her S₁ never had his health card and when he ran in for an emergency. She thought it was a joke as he had just gone down the street, don't be ridiculous.

48. The doctor said "Oh no ma'm, this is a very serious situation and that's when M asked him if he thought S₁ was going to make it. The doctor said he did not know.

49. Then M got on the phone to J and C, whose son S₂ was with. M called there and J said their S₂ was not there and they thought he was over at another boy's place.

50. He told M to get herself ready and they would call around and see if they could find S₂. They could not locate him so finally C and J told them to go ahead to the hospital and they would get hold of S₂ and keep him with them.

51. In the mean time the S₁'s girlfriend had called having already called once before that evening. M told her the situation fast and said she had to go and that she would get in touch with her..

52. M says F just sat there and she guessed he must have realized by the tone of her voice while she was on the phone. When she got off the phone he came up and they just got dressed.

53. M asks F how he remembers it (the situation). She remembers that they did everything automatically. She says they just knew enough to put their clothes on and grab her purse and lock the door and that was it. F agrees and M adds that with that they were gone.

54. M says it was the longest 40 goddamn miles of her life.

55. F says that they did not know what they were going to face when they got there.

47. M's first response was to think that this was a joke since they often had received such hospital calls on S₁'s behalf as he was often without his health card. M believed this to be ridiculous as he had only recently left home.

48. When the medical expert stated the situation was very serious M then asked if he believed S₁ would survive to which he said he was unsure.

49. M tried to locate S₂ by calling the parents of his friend and found he was elsewhere.

50. When efforts to locate S₂ failed, the friend's parents offered to locate and care for S₂ while M and F went tot he hospital.

51. Meanwhile S₁'s important other called and M gave her brief information and promised to contact her later.

52. While M spoke on the phone to the medical expert F sat and listened. She sensed he realized the situation from her voice so that when she completed the phone call they simply prepared to leave.

53. M wonders how F remembers the situation. From her perspective, all activity was automatic and consisted of only the essential such as putting on clothes, grabbing her purse and locking the door to which F agrees.

54. For M the distance travelled felt like the longest in her life.

55. F remembers not knowing what to expect on their arrival at the hospital.

56. M remembers holding hands all the way in and just hanging on for dear life because she felt like her whole world had just caved in.

57. M says she was not quite sure and not knowing where S₂ was, was the worst thing. She said with a low laugh that it was almost like she needed to see the body and the face (of S₂).

58. M says "poor S₂" and tells him to tell his experience of the whole thing. She adds "that was something".

59. S₂ says he (and his friends) had just gone to a friend's. He thinks they told his friend's mother that they were going to the other friend's place - that was in [the nearby town].

60. When they came out they saw the accident but S₂ (didn't know). They didn't say where they were going, that was sort of their escape. They were coming back and S₂ saw the tow truck and it was towing a transport and he thought "Oh shit, if that transport was in an accident, there's really going to be death's in this one".

61. When they got back to his friend's place the friends parents were asking where they were, where S₂ was. When they (fellows) came in, they told them that they were just checking out an accident down the road. The parents told S₂ his brother had been in an accident.

62. S₂ guesses he sort of just sat there. They told him they didn't know what was going on but his brother had just been airlifted to [the city]. M adds that the friend's parents then called the hospital.

63. [I: *What went through your mind when you said you saw the accident and they said your brother was in the accident?*]

56. During the trip M held hands with F in an attempt to "hang on for dear life". She felt as if her whole world had just caved in.

57. The unknown whereabouts of S₂ was most distressing for M. She felt she needed his actual presence for reassurance.

58. M indicates sorrow for S₂'s experience and asks him to share his story.

59. S₂ believes he had gone visiting with a friend in a neighbouring community and had told the mother of his friend their intentions.

60. Upon leaving the second friend's place S₂ and his friend came upon the accident and saw the tow truck with the damaged transport truck. S₂ was shocked to see the damaged vehicle and envisioned the potentiality for a fatality.

61. On returning to his friend's home the parents urgently requested for S₂ and informed him of the accident and the involvement of his brother.

62. While concrete facts were as yet unavailable, S₂ was informed of his brother's transfer to a trauma hospital in the city and his parents were notified of his location.

63. I asks S₂ for his thoughts when he connected the notification of his brother's involvement and his recollection of the accident scene.

64. S₂ says that at first it was hard to say something. He (at first) thought they were talking of his mother and father and then they said that his brother was in the accident. S₂ says its sort of blank, he figured it was a joke — Its pretty bad ... critical.

65. [I: *Do you remembers what the night was like for you? Waiting till your mom and dad came back and you heard from them?*]

66. S₂ says he just sat there and guesses he sort of fell asleep.

67. [I: *What about for you F?*]. F says that when he thinks back about the ride in he guesses it was sort of in stunned disbelief. He knew it was obviously serious but he didn't really want to contemplate how serious things could be. The whole thing was just sort of like a blur.

68. [I: *A dream?*] F says it was almost that way because he knew they would not know much until they got to the hospital.

69. [I: *So, you stayed that full night at the hospital.*]

70. M says they did not go home that night. F says it was almost all night.

71. M adds that when they got to the hospital S₁'s girlfriend was there. She had had her father bring her to the hospital and they happened to meet in the room and they stayed with them she guessed for a couple of hours. They stayed with them until the doctors came.

64. Initially S₂ found it difficult to speak believing his parents were involved prior to being told it was his brother. He went blank and thought it a joke.

65. S₂ is asked what he remembers of that night, what the wait for his parents was like.

66. S₂ remembers sitting there and thinks he fell asleep.

67. I asks F what the night was like for him. Remembering the ride to the hospital, F recalls a feeling of stunned disbelief and though he sensed the obvious seriousness he simultaneously feared to consider the extent of the seriousness. It was a blur.

68. F agrees with I that it was almost like a dream for they realized they lacked any concrete knowledge until they reached the hospital.

69. I asks if they stayed the full night at the hospital.

70. Parental recollection varies with M believing they stayed all night and F believing it was almost all night.

71. M adds that on arrival they met S₁'s important other and her parents who stayed with them several hours until the medical experts arrived.

72. M says there had been a mixup with the health card. There was another person with the same name whose parents had also been called and told that their son was in a serious accident. M states that there was a lot of confusion and commotion. M says that you know you have that split second of maybe they're wrong, it's not my son, you know what I mean but you know it is, not because you've seen the ambulance and you know they've gone there. Since the card was lost they had to go in and identify their son.

73. M says that when they came out the girlfriend and her mother and father were there and they stayed with them. M says that though S₁ and his girlfriend had gone out for 2 years, they hardly knew her parents.

74. M says they were really good and stayed with them for a couple of hours and then they went home, because there was nothing they could do.

75. M says all they were doing was waiting until their S₁ was moved to intensive care and then waiting for the doctor to come in and talk to them which he did after the parents had left.

76. M says she thinks the only reason they went home was that they were desperate to get their S₂. She asks if I knows what she means. She adds that they just wanted to see him and have him with them.

77. [I: *So you came to see S₂ and then went back?*] M says they went home and slept for an hour or two. F says he does not remember but they went back the next day.

78. M adds that when they were up their S₂ came home about 8 am. They had called over to where he was staying when they felt it was a decent enough hour and he came home in 5 minutes or so.

79. M says they showered and went back in (to the hospital).

72. M remembers confusion and commotion due to a mixup of health cards resulting from the admission of another person with the same name. Another set of parents had also been notified of a seriously injured son. The lost health card necessitated their presence to identify their son.

73. Returning from the identification M and F were met by S₁'s important other and her parents whom they hardly knew despite their relationship of several years.

74. M appreciated their presence. They left after several hours since there was nothing they could do.

75. Waiting predominated their time at the hospital; for S₁ to be transferred to intensive care, for the medical expert to talk with them.

76. Desperation to see S₂ and have him with them was the underlying reason for their return home. M asks for affirmation of I's understanding.

77. I reiterates that they came to see S₂ and asks if they then went back. M remembers returning home and sleeping for a short period while F does not remember but believes they returned to the hospital the next day.

78. M called for S₂ at an early but respectable hour and he promptly returned home.

79. They departed for the hospital as soon as they readied themselves.

80. M says she thinks they stayed in [the city] for at least 3 or 4 weeks, staying with her husband's parents and thank god they had a house on [M Dr., west end).

81. [I: *Did you go to work at all during that month.*] M says no.

82. [I: *You were just at the hospital? How long did you stay at the hospital, like from morning till night or*] F says he thinks it was after 9 before they would leave (at night) and they were there by 10 (in the morning). They had been told not to come before 10 as the doctors do all their rounds before then. F adds that they would never leave before 9.

83. M says there were exceptions, days where they didn't (go in early), they would have shopping days when their S₂ needed clothes or there were so many lawyers and insurance people.

84. F wonders about meeting with the lawyers M replies she is sure they saw the insurance (people) within a week. They wanted to see them right away. She remembers that they had to meet the lawyer at one point.

85. M states that she then had problems at work.

86. [I: *You had to notify them right away, you weren't going in for*] M replies that yes they notified them, she guesses that they called them that first morning before they went back to the hospital and after they had gotten hold of S₂.

87. [I: *Now S₂, you weren't going to school? Were you working part time?*] S₂ says he was not going to school and was not working.

80. M believes they stayed in the city for several weeks lodging with F's parents.

81. On questioning, M states they did not return to work during this time.

82. I asks how they spent their time during the early weeks. F reports their days were spent at the hospital from mid morning till mid evening having been advised against appearing before mid morning so as to allow the physicians their time to attend to patients.

83. M reports there were periods of time when they attended to practical matters prior to visiting the hospital (shopping for S₂, meeting with lawyers).

84. F is unsure of their meeting with professional but M remembers that from early on they had to meet key professionals (lawyers, insurance people).

85. M reports the beginning of work-related difficulties.

86. I asks if they notified their respective places of employment of their need for leave from work. M believes they advised their respective employers the first morning prior to returning to the hospital.

87. Upon inquiry as to S₂'s situation, he states he was not involved in school or working.

88. [I: *What was the time like for you? Being in town, going to the hospital all day?*] S₂ says the days were awfully long. He adds that he had just started going out with a new girl at the time and it was kind of hard in that he wanted to see her too. [I: *Did you start coming back out here before your parents came back?*] S₂ started coming out to the house before his parents went back. He thinks it was 3 weeks when he started coming out each weekend and then once during the week. His friend's parents asked if he wanted to come out on the weekend from the hospital.

89. [I: *When you came back out to the house, about, what, 4 weeks after the accident, then did you sort of set up a schedule of coming and going to visit him? How you do your work or what you were doing. What happened?*]

90. F says they never had a schedule and M says they never set anything up. For the 4 months that their son was there (in hospital) they basically came home at night exhausted. They went to bed. They ate. M restates and apologizes that no they never ate at home. They never had to worry about the dishes as they never ate at home and their S₂ took care of his own things. They would get up in the morning, have a shower and talk. If there was anyone they had to meet that morning, they would do that and get it over with. They always got those things over with and anything to do with her work or her husband's work no matter how stacked up the morning was.

91. M says they were available pretty well from noon on at that point. F adds that at that point it was obvious that they (at the hospital) were not going to be doing anything for S₁. S states that very quickly they started to look into head injuries and what it was all about and the aftermath and stuff like that.

92. F adds that soon they became aware of possible treatment plans, coma stimulation and stuff like that. He states that there was none of that in the hospital.

88. For S₂, the days felt exceedingly long and the situation was exacerbated since he had recently met a new girl whom he wished to visit. Consequently he returned to the family home on an intermittent basis in advance of his parents.

89. I asks if they set up a daily visiting schedule once they returned to their home at approximately four weeks.

90. According to F, there was no schedule. For M nothing was organized. Over the four months of S₁'s hospitalization they returned home nightly, exhausted. Since S₂ cared for himself M and F used their home solely to sleep, attend to their personal care and to organize the coming day's events including urgent work-related issues if required.

91. With practical issues attended to prior to noon, they were thus available to attend to S₁. Early on they realized the unavailability of appropriate services for S₁ which spurred them to learn about S₁'s condition and what they might expect in the future.

92. According to F they quickly became aware of specialized treatment protocols and the fact that this hospital did not provide any of these services (coma stimulation program).

93. F says that therefore part of their life was to get in there (to the hospital) because at that point S₁ had opened one eye up. His turn became to go into the hospital and do what they figured the medical system, they presumed should be doing for S₁.

94. F states that that was the way it was. One of the books they had read on coma stimulation (voice becomes louder and more forceful) stressed that in the first 6 months you must be very active in getting them (patient) out of that coma as fast as you can. He adds that the research that they had done demonstrated the fact that the faster people came out of coma, the better the eventual result would be and so it became very pressing for them to get there. Also a lot of time was spent thinking of things they could do and they brought all sorts of various things that had various sense to them.

95. F says that he sort of forgot that this whole thing sort of became their life. Their focus was to get to the hospital and do for S₁ what they could.

96. [I: *So that, you said was the first 4 months. And then what happened?*] F says that at that point S₁ became medically stable and then adds that they were fed up with the hospital.

97. [I: *That was from last January till?*] M says it was from Jan. till April 28th and then says no, S₁ came home on the 28th.

98. F says that it was before that point. There was about a month when they talked about taking S₁ home. They knew they had to arrange for equipment.

99. [I: *So as of now since S₁'s accident he's uh, it's uh 10 months?*] F says that no it was going on 2 years. [I: *Okay, how long has he been home now?*] M adds that the accident was in '92. and since then it has been 19 months.

93. Consequently F and M devoted part of their lives to try to provide S₁ with the treatment they presumed should have been forthcoming from hospital staff but was not, as he was showing limited signs of arousal from coma.

94. As a result of their reading on specialized treatments (coma stimulation) for patients such as S₁, they learned of the urgency to actively try to reduce the duration of coma so as to maximize a positive outcome. It became vital to them to ferret out ways of stimulating S₁ and in turn actively working with him

95. F has almost forgotten how helping S₁ while hospitalized almost took over their lives. They were totally preoccupied with helping him.

96. At approximately 4 months post-injury, S₁ became medically stable and the family was becoming exceedingly frustrated with the hospital.

97. I asks how long it has been. M says this has been from January to April and corrects by saying S₁ came home end of April.

98. F says they began talking about bringing S₁ home approximately one month prior in that they knew many arrangements had to be completed.

99. I mistakenly states that 10 months have passed since the accident and M corrects this to 19 months.

100. [I: *How have things started to change for you, you know that I asked you to write down what had changed and that's. Was there a change and then you moved from that or was there sort of the gradual evolution of the changes that are occurring.*]

101. F says that he thought the writing was on the wall pretty fast for them. He knew that life had changed on them overnight. He doesn't think there was a slow evolution part of realizing that life was not going to go back. He can't remember exactly at what point but it was early on when they realized that life had changed forever.

102. F says he never spent a lot of time focusing on how life had changed for them. Their focus became how they were best going to cope with looking after S₁ at home and what they could do to help him and speed his recovery along as well as how they would have to change the house.

103. F states that some of the time at the hospital was a teaching for them, for seeing what was required in S₁'s care. They basically took over looking after S₁ in the hospital because they needed to know. [I: *That was you training?*] F agrees and adds that (it gave them a sense of) what it was going to be like because M was going to have to handle S₁ by herself, what equipment was required and what did they have at the hospital, how did they do things. So it was like a training course for them.

104. F asserts that there was never, never a moment were they debated would they or would they not bring S₁ home.

105. F adds that it was just a natural course, that was how important it was that they bring S₁ home. Once they realized that he would not be going to [the city hospital which provided inpatient head injury rehabilitation] for rehabilitation.

100. I queries how things have started to change for them and wonders if the changes are gradual.

101. F recalls the almost immediate realization of their dramatically altered life-world. Though difficult to demarcate exactly F believes the awareness of the impossibility of returning to their former way of being became unmistakably obvious very early on..

102. According to F, rather than dwelling on the changes to their life-world, their attention became rivetted on how to best provide for S₁ (at home, what was required to maximize his recovery process and how to adapt their home to accommodate for his needs).

103. During the latter part of S₁'s stay in hospital F and M used that time to train themselves in how to care for S₁ when he came home, to become familiar with necessary equipment usage and to get a sense of what it would be like for them to be responsible for S₁'s total care.

104. F firmly believes there was absolute agreement with the decision to bring S₁ home.

105. F experienced this decision as natural and indicative of their commitment to S₁ once they realized he did not qualify for transfer to a local rehabilitation facility.

106. [I: *You mean when they told you.*] F adds that at one point they thought, early on, that when S₁ might be stable he would probably be going to [the specialized hospital] but after awhile it became clear that if that happened it was going to be a long time that would pass and so they needed to get him home. They knew that this (home) was the best place for S₁ as he certainly wasn't going to get loving care from the hospital. He was just a patient there and they can do that at home.

107. F states that they would also be in control. M asserts that control is the word. She adds that you lose your control in a situation like that. You lose, you have no control over anything and this was their only way of dealing with the situation.

108. M says that she knew too and she was sure for S₂, that the travelling back, and even though he is independent, he is on his own and stuff, there's a big difference between being independent and at least your parents are home at night.

109. M states that when they told S₂ that they were taking S₁ home and she wants to mention this point because she thought it very strange. She believes the social worker said "are you sure you want to do this, have you thought of S₂?" M says she replied that that was the number one thought they did have (voice gets louder) for S₂ whom she says was berserk when they told him they were bringing S₁ home. S₂ thought that was great that they were taking S₁ home.

110. M says she does not understand why they (hospital staff) thought that that (bringing S₁ home) could be a problem for S₂. She adds that with S₁ there (at the hospital), what could be worse, going back and forth to the hospital? S₁ snorts very loudly. M says having everybody there (at home), they were all there.

106. In the early days they anticipated S₁'s possible transfer to a specialized rehabilitation facility. Over time it became clear that given S₁'s rate of progress, it would take a long time for this to occur. Consequently they decided home was the only place they could guarantee specialized loving care.

107. According to F this would also insure they would have control over the situation. For M having control was paramount since control over everything is lost in such situations.

108. M felt that their decision would also benefit S₂. Recognizing S₂'s independence, M nevertheless believed their presence at least in the evening was important.

109. M remembers that S₂ was ecstatic and in full agreement when informed of their intention to bring S₁ home. M thought it highly peculiar when a hospital professional challenged their decision in terms of its affect on S₂ to which M vehemently replied it was one of their primary reasons.

110. M was puzzled as to why hospital staff considered their decision potentially problematic for S₂. To her, being together at home seemed decidedly better.

111. [I: *Could you tell a little bit about what that was like for you, to find out, that you were actually going to come back home?*] S₂ says that he sort of liked the idea because he was there all week by himself and it never seemed like anyone was ever at home and after some big trip into [the city] and stuff like that. He adds that this way he could wake up and S₁ was there, he would be at home, all right and stuff like that.

112. [I: *Did you think about how things were going to be different at home when S₁ came home?*] S₂ replies no, not really. [I: *That was not a high concern of yours?*] S₂ replies that no he could never see the big picture of how things were going to be, going to change. [I: *Thinking back now, do you think that's something that maybe you should have been thinking about or are you still convinced that maybe that really is secondary to the fact that S₁ is now home?*] S₂ replies that that was basically it. It was more important that S₁ was there and stuff like that. [I: *Well that was the sense that I got from reading.*]

113. F states that he thinks they all see the home, that they have a pretty good family unit and even though they're young men and everything evolved the way it was supposed to evolve.

114. F says there was a period where they (S₁ and S₂) rebelled against them and he didn't. He can still remember himself going through those years and thinking back and wondering gee, why was he so rough on his dad. He adds that's the real life, that is a normal part of growing up and gaining independence. He saw that in his own sons and they were becoming independent.

115. F says his only concern with them was that he wanted to make sure that they were educated or had some sort of training so they could live their own lives.

111. (When asked to tell about his reactions to learning of his parents decision to bring S₁ home), S₂ admits he approved of his parents plans in that he was often home alone and it seemed as if no one was every home. It meant he could be assured of his brother's whereabouts and his well-being.

112. On questioning, S₂ did not reflect on the changes which might occur once S₁ returned home. He admits to not being accomplished in envisioning events. For him having his brother at home was the most important issue to which I observes the concurrence with his written response.

113. F believes all family members experience home and family positively despite the fact of their ages and their growing independence.

114. F recalls a time of rebellion from both sons. Reflecting on his own adolescent years he wonders how he could have been so hard on his own father yet he understands it as a normal and necessary part of gaining one's independence and equates it with his own sons' growing independence.

115. F states his sole concern for his sons was the availability of education or training which would enable them to live independently.

116. F does not think there was any doubt in either of their minds (S₁ and S₂), that, in times of trouble, this was always the place to go, that they were always welcome there. F says there was always an ear for them and concern for them.

117. F says that once this (the accident) happened to S₁, it just seemed a very natural evolution to bring him back and look after him again.

118. M states that before the accident S₂ was never home. She adds that when she says never home he wasn't, he'd come home from school when he was still in school, make his own supper and be gone. Then he would come home at 9 or 10 o'clock at night and go to bed. She says it was like "Hi S₂, have a nice day, goodnight S₂, have a good sleep".

119. [I: *That was okay with you?*] M replies that well it was and it wasn't. She says they missed S₂'s company but then they also realized that you have to let them have, you have to break that tie and let them do their thing.

120. M says that ironically enough, when she stayed at home, from the day she stayed at home with S₁, she does not think S₂, except for maybe a handful of days has not been home every day for supper every day. [I: *Well, things have changed in that way.*] M says yes in that sense.

121. F says he thinks that they (sons) participated enough but they were never, neither of them as into bow hunting as he was and neither had that same desire to want to fly or stuff like that. They participated enough in what he did, like in the spring both S₁ and S₂ came on the [flying derby] F went to. So there was still that.

122. F says it always pleased him that they (his sons) liked to do the things he did. They were his kind of boys, they liked motorcycles they liked that adrenalin rush, a little bit of risk-taking.

116. F believes both sons clearly understood home as a place always open to them, especially in time of need.

117. With the occurrence of the accident it seemed only natural to bring S₁ home for caring.

118. M states that prior to the accident S₂ was only home to eat and sleep

119. When asked how she experienced this M replies she had mixed feelings in that while they missed his company, they also realized the importance of allowing S₂ to break with the family home and start developing his own life.

120. M believes its ironic that S₂ has been home for dinner almost every day since she has been home with S₁.

121. While S₁ and S₂ enjoyed participating with F in some sporting activities, they never seemed as keen as he was.

122. It pleased F when his sons did join him. He experienced them as his kind of boys in that they also enjoyed sports which were charged with some degree of risk (motorcycles).

123. F says he always liked that even though he was well aware of the dangers of some of the things he did himself, the risks he was taking. F says that as long as they were properly prepared he was willing to take that (in a much louder voice) never ever believing that either of them might get hurt, because he never did.

124. M states that not that they didn't get hurt but. F then says the thing is that he can remember S₁ one time having a spill on his motorcycle. F was out working on his boat at the time and S₁ and some of his friends and his arm was all bandaged up because he had, F thinks, he had ripped his fingers apart on a spill on his motorcycle.

125. F says they came in like young soldiers surviving another, another one, and sort of bragging about it.

126. F says he can remember he was SO angry because what was on his mind as the father was, do you realize how close a call you could have had on that motorcycle and its just being fluffed off. F says (paraphrases S₁) "Well, I survived another one, it can never put me down".

127. F says he never, that it came back to haunt him after this accident and he says "oh yes it can".

128. F says that of course at that time he was aware of the dangers of doing those things and that it was not that he was against the motorcycling.

129. F says it was tough for him to listen to them (S₁ and friends) boast about surviving another close call.

130. F says he can remember that S₁ was so angry at him because he flew off the handle at him.

131. F adds that he guesses that in the old days he would no doubt have done the same thing as S₁, had his close calls too.

123. Despite his awareness of the potential for danger, F nevertheless was pleased when S₁ and S₂ also enjoyed these activities. Provided there was adequate preparation, F willingly condoned their participation never believing they would be injured given that he had not.

124. When M point out that S₁ and S₂ did get hurt (on occasion) F recounts an occasion when S₁ returned home with his arm bandaged due to a sporting mishap along with some friends.

125. F remembers them arriving with the air of young soldiers boasting of surviving another incident.

126. F remembers feeling intensely angry and equates his anger with paternal fear and the realization of the close potential of his son for serious injury, in light of his son's efforts to minimize the situation and to express his omnipotence.

127. At the time F never imagined this possibility and recognizes now how this situation has returned to haunt him.

128. F recalls both his awareness of the potential danger as well as his acceptance of such activities at that time.

129. For F it was irksome to listen to the boasting of defying another close call.

130. F remembers S₁'s anger because of F's reproach.

131. F believes that he too took such chances in the past.

132. [I: *But its different when its your own.*] F says yeah exactly. [I: *When it's your child.*] F says that S₁ was in his early twenties and just, its best that he didn't hear them, that he didn't hear them boasting. F asks to take a break.

BREAK

133. [I: *What I'd like to focus on in this section is how things have changed for you, say as a mom or as a dad or as a brother or as a son, type of thing. and you wrote really eloquently about things, and what I sort of picked out was "Gosh, how you had changed as a person, what were the changes that you had to make".*]

134. M replies that for her, she guesses, that having worked at the hospital just those two and a half years, like the night before the accident her mind was really becoming focused on her job and she planned to take courses because she really was getting into it. M explains that it took that long to get your feet wet in personnel, there's so much involved. And so she was really getting into it she thinks. She thought that when they moved to the city there would be courses she was going to take and she was going to do this and she was going to do that and her whole life was focused on her job.

135. M adds that as they have said before S₁ was older and on his own basically and S₂ was well onto the college years.

136. M says that all of a sudden her whole world was different and she was not thinking about work.

137. M says that it was amazing to her, because she says she can't begin to tell how much she loved her job. She adds that I had no idea how much she loved her job.

138. M says it was amazing how, when this happened (the accident), it was like the job never existed. It was absolutely irrelevant to her life and everything became focused around what they were going to do for S₁.

132. F agrees with I that the situation is different when it is one's child and adds that given S₁'s age it may have been wiser that he remain unaware of some of his activities.

133. I begins this phase of the interview by stating that she would like to focus on the changes they have experienced with regard to their respective roles.

134. M recalls that prior to the accident her whole life had recently become focused on her new career and she fully intended to pursue further training to enhance her skills.

135. For M both children were in the process of establishing their own lives.

136. Suddenly her world changed and work lost it importance.

137. It was surprising to M given the supreme pleasure she derived from her work.

138. M's job became irrelevant, as if it never existed and now her entire focus of attention became helping S₁.

139. M adds that not only the 4 months that they were at the hospital with this desperation, they felt they needed to go there and do things for S₁. M states that the biggest need was to take S₁ home, under their wing, under her wing, their wing and be able to do for him all that she could.

140. M states that it is like the role reversed although it is not the same as when S₁ was a baby, although it is the same dependence because he is an adult and he is hurting and he is disabled and so her whole world changed in that sense.

141. M states that besides she really felt like she lost a friend because they were really close and they teased alot.

142. M states that its not to say S₁'s more important than S₂. M says she wants I to understand that its just that they had a, quite a comraderie and S₁ was quite a joker and she really misses that part of it.

143. M remembers thinking in her mind that there wasn't anything S₁ wouldn't have done for her. She adds that it was not the case of well he would do it for her so she would do it for him. M states that it was just the kind of relationship it was. There was a lot of give and take.

144. [I: *It sounds to me that that's the kind of, the way all of you were.*] M and F agree and F adds that they were all kind of close. F says that S₂ knew too that if it was him in the accident they would have been doing the same thing for him too and M says "for sure".

145. F states that they never had any problems i realizing that S₁'s in need and for them to do what they could for him. It would be natural to do that.

139. During S₁'s hospitalization there was a desperate need to be with him and help him. However, their most pressing need was to bring S₁ under their own personal care and give him their very best.

140. M experiences her whole world as changed. She feels her role has reversed yet it is not as it was when S₁ was young. Though he is once again dependent on her, also hurting and disabled, he is still an adult.

141. M states she also lost a special friend.

142. M emphasizes she did not favour S₁ over S₂ but she sorely misses S₁'s joking and camaraderie.

143. M affectionately remembers reflecting that S₁ would have done anything for her not in expectation of a return of favours but more as a tribute to the specialness of their reciprocal relationship.

144. I has the impression of a similar experience for all family members to which M and F concur. F believes S₂ realized they would have responded simiarily for him if required.

145. F recalls the absence of difficulty with regard to recognizing S₁'s needs and the naturalness of their desire to assist as much as possible.

146. [I: *So M, it was as if, that you know, you were also looking to the future more focused on yourself. You know as your career.*] M agrees. [I: *But then, in a split second the focus, the centre was.*] M adds that it went out the window. [I: *It was gone.*] M says out the window.

147. [I: *You did mention that you wanted a one year leave of absence and they denied that to you and you were really hurt by that.*] M says that she cried so much over that, that I will never know.

148. (crying) M says she remembers going to see the executive director. She goes on and says that in the first year that she worked there, the personnel director they had had retired or resigned, actually he went back to school and so there was a lot of shuffling around. She knew nothing about personnel. She can remember when he (the director) took over as, assistant, not assistant director but he just sort of took over the department until they go somebody. and she remembers him asking, telling the director before that, he said "tell M I want her to sit in on the meetings". M says she thought this was great, she was going to really learn a lot.

149. M says that he always treated her like she was special and he told her she was special and all that kind of stuff and they had a great relationship. He was a terrific man.

146. When I observes that M's future orientation and focus were on her own self and career M adds they vanished almost instantly (disappeared).

147. I asks M about the denial of her request for a one year leave of absence and the hurt she felt. M believes no one could imagine how deeply affected she was by this.

148. M tearfully remembers going to the executive director. She recounts that there had been a recent change in directorship and at the time of her arrival the interim director had voiced his confidence in her participation. M was delighted and sensed she would be afforded ample opportunity to learn.

149. M recalls always being treated as special by the interim director and valuing their special working relationship.

150. M can remember going to talk to him about this (leave of absence) because in the middle of it all they got a new director. She (new director) started in the wings as assistant manager in the last year and the assistant manager didn't know M from Adam. She (new director) came from private industry and private industry is a far cry from what the government is like. Its very harsh and stuff like that. M says that the new director didn't know the background, she didn't know where M came from or anything like that. And M sort of got the feeling that somewhere along the line she was trying to get people in there who had experience and M didn't have any. M says she means that she was good enough to fill in all the holes. M says that in any case when this came up M had a feeling this person was behind it all.

151. M went and spoke to the former director, she remembers saying, talking to him and telling him "I don't understand how you can do this to me, this is a case of I'm doing something that you promote as a hospital, you're promoting what I'm doing and you're going to tell me you're not going to give me at least a year's leave of absence, just to see what's going to happen?"

152. M says that's all she asked for, she didn't ask for it to be paid. She was supplying somebody with a job.

153. M says that the (former director) said "Well M, I'll see what I can do". M says that at that point they wanted her to come back in May. She guesses he spoke to them and they said "Well, we will extend it and you can come back July 3rd". M thought "you people are really being stupid. She adds that at that point the finance director had been made their director as well.

154. M says that a series of letters then started and each letter got more and more vicious.

150. M remembers consulting this person about her request after another person had taken over the directorship. The new director had been hired from the private sector and was unfamiliar with governmental methods and awareness of M's circumstances. M believes this new director was behind the rejection of her request for a leave of absence due to her lack of proven experience which was now essential.

151. M remembers speaking candidly to the former director, sharing her distress that the administration was unwilling to allow her time to attend to a family member in dire need of care despite the fact that the facility itself promoted such action.

152. M asserts that her request was for unpaid leave and her absence would enable someone else to be employed.

153. M believes that as a result of intervention by the former director she was allowed an additional three months of leave.

154. There followed a series of increasingly vicious letters between the parties.

155. In the end M just wrote to them and said "You're just accepting this". She says they told her she basically had abandoned her position. They added that they were very kind and very understanding and they were really sorry for her situation but the bottom line was that she could not come back. She was out.

156. In a much louder voice M says that at that point she had, she was so bitter at that point.

157. [I: *That was like salt in a wound.*] M says it was the ultimate.

158. M says she can remember one day sitting there and she was really into a self-pity party this one afternoon. That was the day she got the letter from them saying they really felt they were being good to her because she had told them she was going to write to the chairman of the board which she did and who didn't even give her the courtesy of a hello or kiss my butt answer. M says it was not that she asked for his intervention, she just wanted him to be aware. She also wrote a letter to the minister of health and when they read it they sent her a registered letter saying well, you know we really feel we've been fair with you and you know you have basically abandoned your position etc. etc. and that kind of stuff.

159. M says she cried all afternoon but then she put it away and said "that's it, I don't cry for anybody anymore" And she said to F "no matter what happens, I will NEVER go in the work force again!" M says that was it, it was that day when she (decided) she will never work again no matter what happens.

160. S₁ snorts very loudly.

161. M says she will never enter the work force because if there's a place at a psychiatric hospital and you can't get the support from people who promote what you are doing, where the hell are you going to get it. You sure as hell are not going to get it anywhere else.

155. The letters concluded when M wrote to say she believed they were simply accepting the status quo to which they presented their opinion that she had basically abandoned her position despite their understanding and regret over her situation. The bottom line was that her position had been terminated.

156. M recalls feeling tremendously bitter at that time.

157. M felt this was the ultimate blow.

158. M recalls the day she received official notification of the rejection of her request. She was feeling extremely sorry for herself. The letter was in response to her letters to both the chairman of the board and the minister of health notifying them of her situation and predicament. The letter reiterated their belief in their fair treatment and in her culpability in abandoning her position.

159. M wept the entire afternoon but then put the letter away vowing not to cry for anybody anymore. She pledged to F she would never re-enter the work force.

160. S₁ snorts very loudly.

161. M attributes her vow to never enter the work force again to the lack of compassion and support shown her by those she believed were committed to the provision of such ideals.

162. M says that something died in her that day.

163. M says she can remember and it probably sounds ridiculous, its only a stupid job. But because of the way she was treated there, she was well liked, there were lots of people there that she was really close to. M states that she has not set a foot in that place since and she never will. M says she'll probably, she doesn't go by there, its just hard to look at, so she just keeps going.

164. [I: *What did the job mean to you?*] M explains that she had worked for an orthodontist for 12 years and stagnated. She hated it because the job was so blank. There was just nothing left to it and she just had to get out. So for most of the the 10 years that followed, she just had to get out. M laughs. She says that sounds ridiculous, there are no jobs you see, so you don't up and walk away. And so, all of a sudden she went there (to the psychiatric hospital). Referring to her former boss) M says she left a boss who she knew deep down appreciated what she did but really didn't know how to show it and only appreciated a person after they left type of thing.

165. M says that all of a sudden she walked into a place where people were saying to her, like they were thanking her for doing what she did and (telling her) you do it so well and they were so glad she was there. M says that the first words to her and she had never met the person "oh we're so glad to have you on board, you're going to be quite an asset or something like that. M says that he had only heard the word that she was nice on the phone. She doesn't know where the hell he got it because she had never met him.

166. M says they were very supportive and they were very quick to teach you things. She adds that no, they did not teach, that was wrong, she learned on her own (laughs). Nobody had time to teach.

162. M believes something died in her that day.

163. M realizes it was only a job yet given her experiences she has not returned to her former place of employment despite her positive relationships with colleagues. She even avoids looking at the building while driving by so as to protect herself from re-experiencing the painful memories.

164. I asks M to describe what this job meant to her. M explains that prior to this position she had been employed for a considerable period of time by a private health provider (orthodontist) and had felt stagnant for most of that time. While she sensed her employer's inner appreciation of her efforts there was little overt expression. She remained there due to a depressed employment market.

165. In striking contrast, M suddenly found herself in a place where efforts were noticed and openly appreciated. As well M was told that they believed she would benefit the facility.

166. M felt strong support (from colleagues) at her new place of employment. Her learning was essentially on her own given lack of time for others to teach her.

167. M says they were very quick to treat her like she did have a brain in her head and she could learn these things. And they were willing for her to learn and grope her way through and stuff.

168. M says that for her, it was a whole new learning experience, it was something different. She always liked a challenge anyway and got bored really easily. And there was no time to get bored there because things changed the minute she wrote something on paper. It was already coming down from the government that it was different. So she was constantly working or reading and picking up stuff. It was also computers which she had never been on.

169. [I: *A lot of opportunities.*] M says that the door was just open. [I: *It sounds like a lot of things were opening for you, like you were making decisions about moving back into town, future plans, a purchase.*] M adds her piano.

170. [I: *Yeah, and then your role as a mom changed again.*] M agrees and says that it didn't change in the sense that she was back to when the children were small. It wasn't anything like that at all.

171. M says its just that her focus became S₁ and S₂. Because for S₂ it was not so much that she needed to care of him, its just that somehow she felt that she needed to be there for him. Although S₂ was on his own, he could do his own thing, and they were always there and around for him, she just felt that he, somebody just needed to be there to be the core in that house and uh. Just if he wanted to talk or just wanted to be there or just to say "hi mom and don't bug me, I'm going to bed" It didn't matter. She was the sounding board, to be there for him too.

172. M says that for S₁, it was a case of knowing that at home she could control what was being said to him, what was being done to him, who the professionals were that were coming in. M says that they were cut back pretty quick. It was a bit of protection for sure.

167. M felt her abilities and aptitude to learn necessary procedures was recognized and she felt encouraged to learn and struggle through if necessary.

168. M reflects that this was a completely new learning experience for her. This position met her desire for challenge and precluded boredom. M continually availed herself of learning possibilities including an opportunity to acquire new technological skills.

169. I reflects that there seemed to be a lot of opportunities opening for M including future plans and residence change and M adds a new piano.

170. When I states that M's role as a mother changed, M agrees but adds that the change was unlike her early child-rearing days.

171. M's focus became her children again. However, unlike before when her efforts centred on caring, now she feels a strong need to "be there" especially for S₂, to be a sounding board and more importantly to be the "core in that house".

172. For S₁, her being at home affords control over accessibility as well as the care given to him. Very quickly she limited professional accessibility more as a protective measure.

173.[I: *So in assuming the parenting role you're there as the buffer between your child and.*] M adds and the outside world.

174. M agrees and says she did a complete turn around.

175. F says they were very sensitive to what was being said and done to S₁. It was easy in a hospital, but everybody is just a number, to use an old expression. But your own (family member) its not, and you're very sensitive to it.

176. F says he is very sensitive and he never let, forgot that S₁'s a 24 year old. and the fact that he's hurting doesn't change that one iota, he's still a young man. And his dignity, and respect for his privacy, that has to be there.

177. M says that in the hospital you have no control over that and to a certain extent you can't control that but back at home they can control that.

178. M says that they can say don't come back, you do this, you do that, no I don't want your help thank you, get out. M laughs and says there was alot of that in the beginning.

179. [I: *What it is it like to be a dad now ? What is it like for you?*] F says that some of it, he guesses alot depends on how you see what a father is.

180. F says his boys went through that stage where they sort of leave their mother's apron strings and they start looking to their dad for what the guys do and stuff like that. But they had evolved beyond that point too.

181. F says that now, all of a sudden S₁ is back home and hurting and its like. F sees alot of the role again as a guard and as a provider too.

182. F adds that he also sees his role as having to fight for S₁ and he guesses that's basically because the focus has been sort of forced on him.

173. I states that M seemed to assume the role of a buffer for her child and M adds "to the outside world".

174. M believes she did a complete turn around.

175. F recalls their increased sensitivity to the way care was provided to S₁. While aware of the greater ease of providing care in a hospital setting they also realized that there a person is considered primarily a number but this is not the case with families.

176. F considers his increased sensitivity has compelled him to be continually mindful of S₁'s age as a young man despite his injuries.

177. M believes only at home were they afforded control over the care which was provided to S₁.

178. M adds that at home they can direct, accept or reject the care provided. She notes that in the early days at home they rejected and refused a considerable amount of care.

179. I asks F what it is like to be a dad now. He believes it is contingent on how one defines a father.

180. F notes his boys had moved through the normal stages of male development, beyond the safe proximity of their mother's care and even looking to their dad for male guidance and support so that now they were even beyond that.

181. Suddenly S₁ was back home and injured. F experiences his role as a guard and a provider again.

182. F also feels a responsibility to fight for S₁, a task he feels has been thrust upon him.

183. F says that this is in a sense because he expected that all the medical expertise would descend and see what it could do for S₁. But that wasn't there. So there was that. He expected that their insurance company, since it was a car accident would be right there to make sure S₁ got what he needed. They had to fight for there, with a lawyer though they are cooperating for good legal reasons

184. F says that all of a sudden the euthanasia issue came up. They suddenly realized that it never crossed their minds and they realized that there's a lot of people out there who don't agree with what they are doing. F means there are people out there who think they are very selfish, because there's a whole movement who see how S₁ is being fed through a tube, there are people who see that as a medical treatment and he can see it probably is because the tube was put in there medically and being fed through your stomach is not a normal procedure. In that case it becomes one of those issues where you can just turn that off.

185. F says that angers him an awful lot.

186. F says he can see that that is going to become his growing and of more and more concern especially as it becomes more of a practice. F can see the pressure coming up. [I: *This is where the protection really.*] F says that is right.

187. F says that just recently the [provincial] government stopped funding some of that "Gevity" (liquid diet formula). It costs just under 700 bucks a month and F says he forgets the percentage that they're off but F figures they will over the next number of years talk about \$46,000. that will no doubt come from S₁'s rehabilitation money from his insurance policy.

183. F originally believed that appropriate medical intervention for S₁ would be forthcoming as well as effective management of required services for him. F has found it necessary to fight for everything, even society.

184. F was suddenly faced with the issue of euthanasia. He recounts that they became aware of a population of individuals who do not condone their efforts to care for S₁. They construe his prosthetic feeding device as unnatural and believe it should be discontinued.

185. F feels very angry about this.

186. F envisions this area as requiring increased attention on his part especially as the practice becomes more prevalent. F agrees with I that this area fits in with his need to protect.

187. F cites the recent cutback in funding for certain medical products, one of which (liquid nutrition) S₁ requires daily. Given the difference in cost of a funded product, F is concerned that a considerable amount of S₁'s rehabilitation fund will be required simply for S₁'s nutrition requirements.

188. F says that money should not be touched. He says that as things are coming along, if they don't count on the government, medicare ever trying to do anything for S₁ uh. There may be private sources that they are going to have to withdraw and they're going to be seeing almost \$50,000. of money just being spent on S₁'s nutrition which they can't run to the grocery store and buy. It requires a prescription to get. They find it very strange that the [provincial government] would pick on that, something like that.

189. I[*: So you're having to be political now ?*] F agrees and adds that he doesn't think there's a chance they will win that fight. Its just a matter of....

190. [I: *But your role as a dad, has it changed dramatically?*] F says its a big demand. Its gone back to like when S₁ was a child in a sense that he has to be there to protect him from harm.

191. F says that only in the sense that he never felt he had to protect S₁ from society but now he sees our society becoming a growing danger to S₁ and people like him.

192. F says it does not make him feel good having to do that fighting. He says that as a matter of fact its a source of all the stress.

193. [I: *What about uh, a father of an adult son, that happened at the same time as he is also.*] F says that he feels that S₁ needs to get and have as much of a whole life back as he can have. He stays at home all day with his mother, with alot of women coming in to treat him and this isn't to come down hard on women, [I: *The reality of it.*] but F is just saying that the reason, S₁ is a young man and he needs to do things that young men do.

188. F believes the rehabilitation fund should remain untouched. He is concerned that they may be required to access private sources should the government prove unable to fully fund S₁'s care. F finds it difficult to comprehend the rationale behind this particular cutback.

189. F agrees with I's statement that now he must also be political but he doubts if they will win this fight.

190. In response to I's question about the changes to his role as a dad, F experiences his role as very demanding. Again he feels the responsibility to protect S₁ from harm.

191 However, F never felt called upon to protect his son from society whereas he now perceives society as a grave threat to S₁ and others like him.

192. F dislikes having to fight in this way and notes this as a major source of stress for him.

193. When asked about being the father of an older son F shares his concern that S₁ be able to enjoy as much of a whole life as possible. While appreciative of the care S₁ receives from his mother and other female caregivers, F firmly believes S₁ needs to do things young men do.

194. F says its surprising to say, he can remember a couple of weekends ago here, a couple of M's girlfriend's came up to visit and S₁ was in the kitchen and F was working outside and he came in at one point and said to S₁ "Come on S₁, I'm going to take you outside, you can keep me company while I'm working out there. F says you should have seen the big smile he got.

195. F says that S₁ understands, he needs to do to be with, he needs some male companionship too and that's what he needs.

196. F says that he can't, its only on weekends that he can do anything about that.

197. F says that that is the hardest thing he does in the morning, is get up and leave S₁. [I: *That's what you wrote about.*]

198. F says that the simple fact is that he doesn't want to see S₁ robbed of his maleness. He's not a little boy. F sees early on, some people would come and baby talk to S₁. They had to stop that because, why would all of a sudden, because he is injured. There's something in people's minds that thinks that when you become injured or you become old, now they can talk down to them and treat them like children. And he's (S₁) not like that.

199. [I: *You want to protect again, and make sure that he's treated the way.*] F adds that its also to give S₁ as much of the world back as he can too.

200. [I: *And slowly you're doing th...*] - says about as much as he can and adds that as I says, in the climate we live in, its not easy getting out in the winter time. Its a big job to get out and it will be a bigger job in the winter time. And like he says, its only on weekends, all they have is on the weekends. So that bothers F an awful lot.

194. F cites a recent example when some friends were visiting M. F remembers the heartfelt smile from S₁ when F suggested S₁ keep him company outside while he worked in the yard.

195. F believes S₁ is aware of his interest in male companionship.

196. F regrets only being able to help out on weekends.

197. Having to get up and leave S₁ is the most difficult thing for F (causes F the most anguish)

198. F emphasizes his conviction to not allow S₁ to be robbed of his maleness. S₁ is not a little boy, yet F was shocked to witness others talking as to a baby to S₁. They stopped this but F is baffled as to why people equate serious impairment with being childlike.

199. I notes that F is endeavouring to protect and insure S₁ is treated in an age-appropriate manner. F adds he is also committed to helping S₁ reclaim as much of a world/life as is possible.

200. When I states that F is slowly doing that (helping S₁ reclaim his life) F acknowledges he is giving his best but laments his limited time to do so as well as the seasonal conditions which further limit his efforts and this worries F.

201. [I: *What about your relation, how things are, like as a dad with S₂?*] F says he does not think things have changed a heck of a lot between S₂ and himself.

202. F thinks the family unit may, they have been forced to focus. The family was always important but it was never like in the forefront of their minds. Like they've got to protect the family unit type of thing, But now it is, they see it as very important thing.

203. F says that (his relationship with S₂) S₂ is independent as he ever was and he is free to uh, pursue whatever he wants to do

204. F says that mind you, there's not a heck of a lot to come and do with him anymore. He points out that S₂ is in school also. F adds that even if its to go flying with him or something like that, S₂ has got to study and stuff like that M says that except they worry ten times more that they did.

205. F says that there's that part too, that lightning can strike twice he guesses. And its a funny way to think about it but one down and one more to go. He says he worries about that.

206. [I: *Always wondering when you are going to be caught again?*] F says that's right. M nods in agreement.

207. [I: *S₂ how it is for you with your brother? You wrote some very special things.*] S₂ says that he guesses that he almost feels like he is the older brother now.

208. S₂ says he guesses his mom and dad are like protection and stuff like that. He says that his mom said something about people coming over and stuff like that. They want to talk to mom and dad and say hi or something to justify they came to see S₁ and stuff like that. S₂ says he and S₁ never really did things together because he was.... like older than him and that didn't change.

201. F does not believe his relationship with S₂ has been significantly affected.

202 F believes that though the family was considered important before, it is now perceived to be in the forefront and there is a strong urge to protect it.

203. When reflecting on his relationship with S₂, F views S₂ as independent as ever and free to do whatever he wants.

204. F notes that now there is little for S₂ to do with him and school commitments often preclude him accompanying F on special activities Earlier they drove together considerably more.

205. F worries about something befalling his second son referring to the fact that lightning can strike twice.

206. F agrees with I when she reflects that he seems to be constantly concerned that something will occur again.

207. When asked how it is for S₂ with his brother, he replies that he now feels as if he is the older brother.

208. S₂ experiences his parents now as protection (for S₁) and notes that often visitors say hi to S₁ to justify visiting him despite the fact that they talk more with his parents. S₂ does not recall much interaction with S₁.

209. F breaks in and asks if he can make a point. He says that one of the things they worry about S₁ is the future.

210. F says what if they get sick, something happens to them as they get older and they, and he thinks S₂ is aware that they look at him quite a bit as, to down the road, as going to be possibly counting on him to keep an eye out for S₁ and exactly how that role will be he's not sure.

211. F says he'd be sort of curious, because they never discussed this with S₂. F says to S₂, "how do you think about when you know that we're thinking about that, when we get older and that". F continues "I mean we worry about what's going to happen to S₁ and how he's going to be looked after and what do you think about that, cause you have a life too? S₂ replies "its true".

212. F asks S₂ if he feels like they are putting alot of pressure on him. S₂ says he thinks about that but he's only 19 and he doesn't know what he's supposed to do if they were in an accident or something like that. He adds taking care of S₁ and taking care of the house.

213. [I: *That probably is something you will have to talk about.*] F agrees. [I: *And how to work it out.*] F agrees.

214. F says its certainly not fair of them. They don't want to, they know its not fair to burden S₂ with these things because he has his own life too.

2165 F continues that it is something of a worry for them for they'd never want to see S₁ institutionalized.

216. [I: *Its going to take alot of, or probably as much or more planning than what you have already accomplished to have him i the house.*] F agrees.

217. F says that also where even if S₂ said well we don't have to worry about that, he'll take care of S₁ forever, what if he gets married someday, what would his wife think? Also S₂ may get tired of it.

209. F asks permission to interrupt and asserts that they worry a great deal about S₁ and the future.

210. F worries that they may fall ill or become unable to care for S₁ in later years. he believes S₂ is aware of their hope that he take over for them but how this would be arranged is as yet unclear.

211. Since they have yet to discuss S₁'s future care, F is curious as to how S₂ feels about their concerns and hopes for S₁'s care once they become older. F confides that they worry about S₁'s care as well as how S₂ perceives the situation but they realize S₂ has a right to his own life.

212. F asks S₂ if he feels they are pressuring him. S₂ admits to thinking of such things but being only a young adult he has no knowledge of what must be done should his parents suddenly be unable to care for S₁. He wonders about caring for S₁ and their residence.

213. I suggests the expedience of discussion on this topic to which F agrees.

214. F acknowledges their concern that such expectations may be burdensome and not fair to S₂ and that is not their intention as they realize he is entitled to his own life.

215. F confides that they do worry about this as they "never want to see S₁ institutionalized".

216. I suggests that planning for S₁'s future care may take even more effort than planning his home-coming.

217 F is concerned that even if S₂ were to put their worries to rest and agree to care for S₁ when the need arises, he may marry and his wife may not be of like mind or S₂ may tire of the responsibility.

218. [I: *So now there's big questions that are really profound.*] F agrees and says they don't have any answers for them yet.

219. [I: *S₂, you mentioned that just before S₁'s accident that you were just sort of getting to speak to each other, I guess and share more brotherly, or you know, just chatting and ideas and uh, experiences and that. Because I guess as you were maturing you were becoming more equals. What was that like for you to feel that coming and then all of a sudden the accident? Snatched.*]

220. S₂ says he guesses that when they grew up they sort of fought so much that he sort of hated S₁. [I: *Squabbling or was there really animosity?*] S₂ says it was pretty good. [I: *Heavy?*] S₂ says it was pretty brutal. M adds it was verbal as there were no fisty-cuffs.

221. S₂ says that after S₁ came back he'd talk to S₂ like he was older or something. S₂ guesses that getting out of the house and coming back (S₁) it was sort of better. S₂ says that after the accident he never thought about how it would be in the future and stuff like that. That was basically.

222. [I: *You mentioned that you have a strong sense that S₁ understands a lot of things. I guess if you've lived together, shared things, even though you didn't get along so well. The times you shared space and you know really from early times a lot of things. I was just curious as to what you pick up from S₁ that lets you know.*]

223. S₂ says he doesn't know, he guesses that some of the things his mom and dad say and other people who have been in the same situation. His mom and dad will say that S₂ will come home and start to say something, S₁ will look around and stuff like that. S₂ adds that when you talk to S₁ he sort of, the way he looks at you, the things he'll do when you say something, so it makes him realize he can understand what he's saying.

218. F agrees with I that they are now faced with very profound issues but presently they lack answers.

219. I asks S₂ what it was like to experience a more equal relationship with S₁ and to have this tragedy occur.

220. S₂ remembers when he was younger fighting so much with his brother that there was a dimension of hatred. They were quite brutal though M adds they were primarily verbal.

221. S₂ recalls S₁ conversing with him as if he were older and speculates that was somehow connected to S₁'s previous departure and subsequent return home. Notwithstanding, S₂ did not contemplate the future.

222. Based on S₂'s written description I asks S₂ what he picks up from S₁ and if he can explain how he knows S₁ understands many things.

223. S₂ speculates that his intuition is based in part on the observations of others but also on his own observations of how S₁ looks at him in a certain way and some of the things he does.

224. M asks to be pardoned for interjecting and adds that she can remember when S₂ started coming once a week to the hospital and S₁ was very, very low. S₁ always reacted to S₂. The bond was so strong it was amazing.

225. M says that as S₂ obviously wrote, they really did fight and they hated each other. She says believe me, as much as they thought they did, they did.

226. M laughs and says she can remember when they were young and she would say "you should get along because one of these days you are going to be friends" and that's just the way it was.

227. M says that yet in the midst of all this, when S₁ was so low in the coma and S₂ coming in once a week and S₁'s whole focus would turn to S₂'s voice.

228. M says its amazing and adds that of course S₂ was not aware of that at the time as that was going back over a year now (S₁'s reactions to S₂'s visits to the hospital) M just wanted to mention that because it was just so obvious to them at the time.

229. [I: *I'd like to ask, between the two of you, both of you mentioned about your time, or as a family was closer, and in a way your time in your marital relationship is somewhat closer and more cemented, but yet on the other hand, there's so much. Its moved and its changed.*]

230. F says that for sure, they have a common focus now, they have that one thing they focus on. They really don't have a relationship any other way anymore. They don't have all that time to sit and talk to each other.

231. F says that I said the drive in and the drive back everyday, they were together all the time. [I: *You used that time.*] F says exactly, they don't have that time anymore. [I: *So you've lost that opportunity.*] F agrees.

224. M breaks in to illustrate the dramatic effect S₂ had on S₁ while hospitalized. She attributes the reaction elicited despite the severity of the coma to the bond between the brothers.

225. M corroborates what she believes S₂ wrote about the fighting and hatred between the brothers.

226. M fondly recalls admonishing her young sons to get along as she knew that later they would eventually be friends.

227. M recalls that even when at his lowest S₁ would totally respond to S₂'s voice during his weekly visits.

228. Though obvious to others, M realizes that S₂ was unaware of this at the time. Her sense of amazement leads her to mention this now.

229. I turns to M and F and asks them to discuss the changes mentioned in the written descriptions to their marital relationship.

230. F begins by emphasizing that the mutual and singular focus on caring for S₁ to the exclusion of all other dimensions of their relationship has become the basis of their relationship.

231. As well they no longer share commuting time so that another opportunity for conversation is also lost.

232. [I: *What is that like?*] F says they certainly miss it, that's for sure.

233. F says that its that their focus so much is on S₁ right now. They know that they're aware that its gone, its just that their focus needs to be on S₁ right now and they accept that fact.

234. F guesses that alot of it is that a lot of things have changed, they've lost alot of what they've had, but its so important what they do now and that's just the way it is.

235. F says to M, "do you feel like that?" M say yes and then says no.

236. M says she was just daydreaming back to the times when they, Saturday mornings for instance, when they would get up. She says that this sounds terribly lazy but Saturday mornings they would get up and have coffee and more and they would sit and she says to I, "I'm telling you, we'd sit till noon and just talk and just do nothing else but". She says they would not necessarily talk about the kids or anything like that, maybe they would be talking about going to the dump or anything.

237. M says its those moments she misses. She says that she knows F does too because these were very important.

238. M says its just that wind-down period, on Saturday morning. [I: *There's no agenda.*] M gives a big sigh and says "Oh God", they didn't have to rush out to work and all they had to do was just sit and learn to be friends again because all week they were sort of going their own little route except for the drive in and the drive back which was the only good thing about the drive (laughs). She says that this is a good topic.

232. When asked F reports that he definitely misses this aspect of their relationship.

233. While aware of the changes to their former relationship, F believes they are aware of and accept the need for this new focus.

234. F reminisces that they have lost alot and the changes are great. Nevertheless, being this way is more important, this is their reality.

235. F asks M if she feels the same to which she initially responds yes but corrects herself with no.

236. M shares her reverie of how they used to spend their entire Saturday mornings lounging and conversing over coffee. Their conversations ran the gamut from family issues to incidental local issues.

237. M especially misses those moments and believes F does also given their importance.

238. Given the absence of an agenda, M recalls that they used their Saturday mornings to release their work-week tensions and to rekindle their friendship again. She reflects that this is a good topic.

239. M says that she thinks she too misses, like F, their schedule is so mixed up, like F goes to bed at 10 or so, so he can get a half decent night's sleep because he'll wake at the drop of a hat. Whereas she stays up later because S₁ need to be turned.

240. M says she cannot be bothered, if she goes to bed at 10 well she knows that she's going to get up at midnight. There's no point. So she just stays up and then she turns S₁ and usually its around 12:30, so its 1 o'clock before she gets to bed and then she is dead. M says she means dead, nothing would wake her up and so thank god, F gets, is a little lighter sleeper because if something happens, he'll wake up.

241 F says its sort of funny because when you're younger, he could sleep through anything and a cough from one of the kids and M would be out of bed like a shot. Now the role is sort of different and alot of it is because she goes to bed so late, but she'll sleep through but if S₁ started to gag or something like that F is out of bed like a shot.

242. F says that usually he's up at least once and then he'll wake up, sort of like his own biological clock. He can get up there and check on S₁ and go back to bed. F says that these days it's been 2 or 3 times he'll wake up because S₁ starts to cough and that (S₁ has a cold)

243. F says that during the week he has to get up alone. He does not wake M up until he's ready to leave and go out the door. He adds that they do not have that. F says that even before, they would both get up in the morning and head to the bathrooms to get ready and everything like that and cross paths. They don't have that anymore. F says he is up alone, and gets ready alone. He wakes M and tells her he's going.

244. [I: *So its sort of synchronized, but its.*] F agrees and adds that they're almost, sort of living separate lives. M says she guesses that that's the point.

239. M also misses their time together and cites the need to alternate their sleep time as a contributing factor. F retires first to insure some uninterrupted sleep time and M follows after attending to S₁'s late-night routine.

240. M retires after midnight and attending to S₁. she acknowledges that exhaustion insures a deep, unrousable sleep ad she is grateful that F who is easily roused is then able to take over.

241. F remarks at the irony of the change in each one's rousability. He notes that in earlier days, M was the lighter sleeper and more responsive to the younger children given his proclivity to tune out most sounds whereas now he tends to be more alert especially to the needs of S₁.

242. F relies on his internal alerting system which he equates to a biological clock. Recently he has had to respond to S₁ several times in the night (due to a cold).

243. During the week F wakes on his own, attends to himself and wakes M as he departs for work. They no longer share early morning pre-work time together.

244. F experiences and M agrees their lives are more separate than synchronized as suggested by I.

245. [I: *What about the evenings, like when you're home, is it still the same?*] M says that no, they sit together at the table when they have dinner and they have S₁ up. She always has S₁ up in his chair again at that point. She says that at least they have that together.

246. F says that I has to understand that their evenings are quite short because now when it comes to shopping, (M adds or banking,) like where before they could shop alone, he's alone to do it and he does it on his way home. He says that where they are there, they can't rush back anywhere so any shopping he has to do, he has to do it alone. [I: *So you have to attend to alot of stuff.*]

247. [I: *And you have to make the list beforehand.*] M says that she did all that at lunch (time) because she had an hour at lunch and she worked right beside a shopping centre. [I: *All that has changed dramatically.*]

248. F says it is more common for them to have supper at 8 o'clock. At night S₁ has to be attended to and taken care of and got back to bed and then at 10 o'clock he goes to bed. That's it.

249. F says that even like last winter when S₂ was at college he travelled with F everyday. And it was sort of great to have his company. F says that the rough part was his schedule. M says his (S₂'s) music, laughs and says she's sorry (for interrupting). F says that they came to an arrangement, they listened to his music on the way in and to S₂'s on the way home because S₂ would take the truck after dropping F off. S₂ would take the truck and he would pick F up and F let him drive it and he left his music on. F says that was sort of good.

250. The only problem was that F's working hours changed 3 times a week because there were mornings he had to start working at 7:30 and there were mornings he had to start at 9:30 and trying to synchronize his body for a night's sleep to get around that, that was rough.

245. In response to I's question, M says that unlike before they are all together at dinner time. She makes sure S₁ is up in his chair close by the table to insure some togetherness.

246. F qualifies M's statement by adding that their evenings are significantly shorter since he often must attend to errands on his way home unlike before when M and F were able to complete these jointly.

247. Previously M attended to household errands over lunch hour given her work location.

248. Evenings are now short with dinner being routinely later, followed by attention to S₁'s bedtime needs and F's own early retirement to bed.

249. F remembers enjoying the company of S₂ immensely during their commuting time last year. Their most serious difficulty centred around S₂'s music but they were able to work out an acceptable agreement based on the coordination of their driving.

250. F's varied work schedule proved to be the most problematic in that he found it difficult to synchronize his body clock with his schedule requirements.

251. F says he wasn't looking forward to this year since S₂'s schedule was so bad that there was absolutely no way. So S₂ drives in by himself now everyday. F says that in some ways its good for S₂, in the sense that with all the stopping and shopping that F had to be doing was interfering with S₂'s abilities to come home and study. F says S₂ didn't appreciate that but he just had to put up with it.

252. [I: *How have things changed for you S₂?*]. He says he guesses that he's more spoiled. [I: *Spoiled? Tell me a little bit more about that.*]. S₂ says he just feels like he gets more, like at Christmas. He always wanted a weight set. And this year he actually got one and he has a brand new car now and he guesses that he can talk more to them (F and M) now. He says that they're like sort of like his psychologist or psychiatrist for the moment and he feels, he knows they worry about him.

253. [I: *Do you worry about them?*] S₂ says he doesn't know. He guesses that he still sort of, he's sort of stubborn and he doesn't think that anything is going to happen, sometimes if they're out late he'll start to think what's taking them so long. But deep down inside he says you never really think anything is going to happen.(barely audible, head is down.)

254. M says she wants to add about the stupid car. She says that the reason S₂ got a new car is because they live where they do. They go through a car every 4 years and so there was no point in buying a used car because it wouldn't have lasted.

255. F says that when S₁ was in college they put him up, they got him a place in town, they got him food and stuff like that and it was terribly expensive. So this time they decided it was probably better all around buying one car. [I: *One way or the other.*] F adds that there just seemed to be no options, its seemed easiest to buy S₂ a car.

251. F dreaded the coming year. However, S₂'s school schedule precluded any coordination with driving. Now they drive separately. F senses this arrangement serves S₂'s study needs better in that completing so many errands delayed their return home. F realized this inconvenience for S₂ but admits there was no choice.

252. When asked how things have changed for him, S₂ guesses he is more spoiled in that he now gets not only more material goods but also responsive attention and support from his parents. He is aware they worry about him.

253. When asked if he worries about his parents S₂ says he is not sure. On the one hand he stubbornly refuses to consider the possibility of a demise occurring which he believes is connected to feeling deep inside, as do others, that nothing will ever happen.

254. M interjects and explains that a new car was purchased for S₂ as a sound economic investment given the commuting required.

255. F adds that buying the new car for S₂ seemed like the wisest option given their former financing of S₁'s education and living expenses in the city.

256. F says he does not think S₂ would have thought of it as acceptable to live alone in the city. This way he's at home and

257. M says that that's where they get a little anxious. She says that F said that maybe they could get S₂ an apartment. M says in a very loud voice, " My favourite reaction is are you kidding, this kid will never leave this house and laughing she adds he'll not get married, he'll stay right here." She then says no, that's her immediate reaction, that's what she wants to do and demonstrating with her hands she says "pull him right back here and tie him down".

258. M laughs and says that in all honesty, F is right, she does not think, S₂ would say "what, you'd throw me out, into an apartment?" S₂ says he's not ready to.... [I: *You like the home and a nest.*]

259. [I: *It sounded to me, when I read your example of, to illustrate what it is like to have S₁ at home, the way it affects the family is that life has now become much more complicated and complex, whereas before things were easing off and becoming more automatic.*] F and M agree. [I: *For all of you?*] M says for everything.

260. F says its almost bittersweet in some ways. Its really, it feels good to be looking after S₁, he means it makes them feel real good to take care of S₁ like that but then the other side of the fact is that the natural evolution is S₁ should be an independent young man now. F says there is alot of comfort in knowing what they can do for him.

261. F says that in one way its nice, its like getting one of your kids back but the price S₁'s had to pay for it for them to have this is horrendous.

262. M agrees. [I: *So, given a choice you would.*] F says he would sooner see S₁ independent and see him once a year and know he's glad to see them once a year but the natural evolution is the way it should be.

256. F believes S₂ would not have found living alone in the city acceptable and the car enables him to continue to live at home.

257. The thought of S₂ getting his own accommodation arouses considerable anxiety. M's unedited immediate reaction delivered partly in jest and partly with great force is to decree that he will never leave the house nor will he marry. She adds emphasis by demonstrating holding him by force.

258. However, M honestly believes S₂ would consider having to get his own accommodation as akin to being expelled from his own home to which S₂ indicates he is not yet ready to leave (the security of home).

259. When I suggests that from their written descriptions she senses that life is now more complicated and complex unlike prior to the accident when much of life was becoming easier and more automatic both M and F agree and state that this transcends all domains of family life.

260. F describes their situation as almost bittersweet in that they experience comfort in knowing what they are doing for S₁ but they also realize that his natural evolution toward independent manhood has been impeded.

261. F feels as if one of his offspring has been return to him but cites the horrendous price paid for such an experience.

262. M agrees and adds that they would sincerely prefer to see S₁ infrequently and to know that he is able to experience the natural evolution of his life toward personal independence

263. F says its on going two years and he never loses sight of the fact of what S₁ was before.

264. [I: *Has your perspective on life changed?*] F says in some ways he is bitter but that he is sort of bitter because he didn't see a lot of resources coming out to help them. He says he is almost wondering if there had been a whole system out there geared up to help people like S₁, would things have been different. Would he be further along now. Would he be better on. F does not know.

265. F says that all he knows is there was NOTHING there to help them. They had to use their own imagination to do it.

266. F says they had to put up with an awful lot of flak because of it too. It wasn't just that they had to put up with what they did, there was almost in some cases open hostility for what they were trying to do.

267. F says that was sort of a shocker to him. He didn't realize that. He says that one would almost think that some of those strangers were as concerned about one's son's health as he was. They suddenly realized that that was not the case.

268. [I: *How about for you M?*] M says it was funny for her. She says she was always very, what people called outgoing and social and people used to think that she would be great at a party and she was this and she was that and she says it was amazing how little people knew her and how little she cared. M asks I if she knows what she is saying. M says that she found that she does care about people, she does not mean that she does not care.

269. M says that it was amazing to her when this happened, how all these people who thought that she was so social, as much as they thought they could help, they were so useless and didn't have a clue how to face the situation. M says she's talking about family as well as friends.

264. F never loses sight of how S₁ was before the accident despite the passage of time.

264. I asks if their perspectives on life has changed. F feels bitter primarily because assumed care was never forthcoming. While F questions whether acquisition of appropriate therapeutic care for S₁ would have made a difference in his progress, he has no answers.

265. F vehemently states there was absolutely nothing there to help them thus forcing them to rely on their own imaginations.

266. As well F remembers having to withstand considerable dissension often bordering on open hostility for their efforts to help S₁.

267. F was shocked when they suddenly realized that these strange professionals were not as concerned with his son's health as they were.

268. M perceived the situation as curious. Though considered by many as outgoing and sociable M now finds herself as lacking interest or concern for others.

269. M was amazed to realize the outright ineptitude of those who gave the impression they could help in such a circumstance. Included were family members as well as friends.

270. M says that the people they expected it most from, they got the least from. And the people who they knew from Adam were saying that they'd say a prayer for S₁ and it was sincerely meant. M says it brought tears to their eyes. And that it left her feeling um, let down she guesses. She asks I if she knows what she is trying to say.

271. M says its just the feeling that like, in general, that she really can't be bothered anymore and she really doesn't. She does not socialize with their friends, she rarely calls them and if they call her, then that is fine, but she can't be bothered.

272. M says they don't have a clue what's going on in their lives. They never asked. Her sister-in-law, who was there and which M thinks she wrote about, who is F's brother's first wife is the ONLY one , except for her mom who had asked M the week before, what her day was like. M's sister-in-law would have come alot sooner except she hasn't been able to, she's taking care of a grandchild and she's kind of stuck at home. M says she was the only one who had enough in her to ask what M's day was like, what it is like to take care of S₁, what she did and who comes in.

273. M says she looked at her sister-in-law and she couldn't believe it. In a year and a half, she was the first person who had ever cared enough to ask.

274. M says that most people are afraid to ask because they really don't want to know. Basically that is what she has realized. People don't really want to know the stuff because they really don't want it to interfere with their own lives she supposes but she's doesn't know.

275. M says that one gets to the point where you just sort of, like "go away". M adds that your perspective on it is. [I: *To keep the disappointment away.*] M agrees.

276. F says he still thinks alot of people don't understand why one's life has changed, most people ideally are.

270. Contrary to expectation often those expected to be of greatest assistance seemed to provide the least while some complete strangers offered genuine interest and support which touched M deeply. At bottom M feels seriously dejected and asks for understanding (reassurance).

271. M experiences a general lack of energy or interest to continue social niceties. She rarely interacts with friends but reciprocates when contacted.

272. M sorrows that most lack awareness of what is transpiring and notes this is primarily related to lack of inquiry. Outside of her own mother, only a former relation on a recent visit asked how it was for M to care for S₁. M felt this was the only person willing to ask such a question.

273. M gazed in disbelief realizing that this was the first person since the accident occured who seemed to care enough to inquire

274. M believes others are reluctant to inquire out of fear of realizing her reality. It seems to M that others prefer to retain their own ideas of how a cure should come about.

275. M believes people get to the point where they prefer the absence of others, in order to defend against disappointment.

276. F believes most individuals lack any understanding of why a person's life changes under such circumstances.

277. M says that they (other people) haven't even asked so they don't have a clue.

278. F says that his life should now be back to the way it was before. They (others) don't seem to have a, they never ask, so they don't have a clue about what their concerns are and what they are dealing with. F says they figure its been 2 years, life should be back to exactly the way it was before.

279. F says that people who he works with will, after awhile, ask him if he's going hunting this year. He knows now not to say along, maybe I'll get a licence I don't know, I'll see. F says he doesn't ever try to explain to people anymore because he realizes that its a waste of time.

280. F says that he has other concerns on his mind now, without worrying about hunting. F says that they (people) say that it is the time involved and he just doesn't have that time anymore.

281. F says he can't put everything into it anyhow and adds that when you are up a couple of times in the night you're not going to be getting up at 3 o'clock in the morning and head out into the bush to climb a tree. It doesn't exactly turn him on either.

282. F says he just stopped saying things to people, people he's worked with for many many years. Some of them have never to this day ever inquired about S₁, not one word, ever mentioned. M adds that he has worked there for 30 years.

283. [I: *Its like a lonely life, you're really bother.*] F says definitely. M says that they are on their own. They are on their own in every aspect.

284. F says that they (people) don't want to hear the down side of anything, only the bright side of everything. And they don't want to hear about the way things could be or the worst of it.

277. M attributes their lack of understanding to the absence of inquiry.

278. F senses the assumption of others that his life should be back to its former way given the passage of time. However, with the absence of inquiry they remain ignorant of his concerns or experiences.

279. F gives the illustration of work colleagues who inquire if he will participate in a favourite seasonal sport. He now refrains from offering tentative responses nor does he try to explain having come to the realization of the futility of such efforts.

280. F admits to more pressing concerns than interest in a sport. While others suggest time involvement as a limiting factor F amends this notion to no time for such involvement.

281. F acknowledges lack of energy for such pursuits citing lack of adequate sleep to effectively carry out this sport. More importantly he now realizes a genuine lack of interest.

282. F no longer shares information with colleagues many whom he has associated with throughout his career noting that most have never inquired as to S₁'s condition to date.

283. I reflects that it seems like a lonely life to which M emphasizes that they feel completely on their own in every way.

284. F senses that most people prefer to hear only the positive and to avoid the negative especially how things might be.

285. M says that F's parents just want to, they kept on saying that S₁ was going to be 100%. That's it. They didn't want to hear any more. So they just say, "what", walk away and don't think. She asks if I knows what she means.

286. [I: *But it leaves you feeling like a*] ... and M says resentment.

287. [I: *alienated almost.*] F says there's no question about that. Without each other, maybe that's one of the reasons why he said before he feels the family unit is so strong because they're about the only people other than other people who have been through this that understand what this is.

288. F says that even at that, they sometimes wonder about other people who have been through it, because they have been in contact with some people and he doesn't understand why there's so much push on them to get away from S₁ all the time.

289. F says that to not understand that, they're not looking for a life to get away from S₁, they're looking to make a life where S₁ comes with them. He says that that's the only thing that works.

290. F adds that he gets sort of annoyed after awhile with people telling him that, and laughing he says he's 48 years old and he doesn't need any advice thank you.

291. F says he shouldn't say that, he means that people can express things but after awhile one gets sort of tired of people starting to tell to you that

292. M says that its just the trite things they say, like "take a vacation". She says that these are professionals doing this and they're there. M says "take a vacation, what do you care? "take a vacation and very loudly she says we don't have any goddamn vacation. [I: *What do you mean?*] M continues yeah, go away to Florida for a week and forget your problems? Are you kidding, there's no way.

285. M refers to F's parents who remain firmly convinced of S₁'s total recovery and reject hearing more. M and F have chosen to disregard and ignore their comments.

286. For M, it feels like a deception.

287. F concurs with I on feelings of alienation and further suggests this may contribute to his perception of a strong sense of family (cohesiveness) in that outside of others with similar experiences only their immediate family seems to fully understand what this is like for them.

288. F questions the understanding of some with similar experiences. He finds it difficult to comprehend the insistence by some of the need for them to take a break from caring for S₁.

289. F corrects the mistaken notion of those who believe they need to get away. What they especially desire is to find ways that S₁ can accompany them. That is what they need.

290. As a result of such urgings F has come to realize that at his age he no longer needs the advice of others.

291 F back tracks and concedes others are entitled to express their own views but admits to exasperation at hearing such suggestions.

292. M enters the conversation adding that the trite comments are the most irksome. She refers more specifically to professionals who suggest they take a vacation. Sarcastically M shares that they have no vacation time. Furthermore she finds it incredulous that anyone would consider the possibility of them being able to leave and forget their problems.

293. M says besides which. [I: *The notion of a vacation is completely different for you.*] F agrees.

294. F says that they know damn well that if they went off somewhere the only thing they would ever be thinking about is how S₁ is making out.

295. F says that perhaps if S₁ was better than he is right now, more aware and could voice his concerns, then that would be a different thing. But right now he is quite helpless and without them being there to guard him, F guesses it out of the question.

296. F says that its the same sort of thing as the people said to him, that he must find going to work takes alot of stress off his back. And he finds that such a strange comment. (He wonders) well do you really think that when he goes to work that he just forgets about all, what is back at home.

297. F says he means, he guesses that there are some moments when he is concentrating on his work. But do they really think that because he has left, he has walked out the door that its gone, that he doesn't have any worries.

298. M asks S₂ to move S₁'s chair back a bit and then thanks him. S₂ gets up and tilts S₁'s chair back and then sits down.

299. F says that that falls in line with alot of trite comments.

300. [I: *Do you find, you start feeling angry?*] F says there are lots of moments of anger, there's no question about that. M adds that it (F's anger) is very quick to surface she might add and laughs. She says its amazing.

301. F says that the thing is that he has to control himself. He basically doesn't talk about S₁ anymore. There are few people, strange enough, most of them are people he didn't really, he never socialized with them at work who obviously ask questions about S₁.

293. I reflects that the notion of a vacation is completely different for them to which F agrees.

294. F firmly believes S₁ would be their only concern if they ever went away.

295. Should S₁'s condition improve to the point where he could voice his concerns and be more aware, the situation would be different. Until then, given his helplessness, they feel bound to stay and protect him.

296. F equates suggestions to take a vacation with statements regarding his work being a diversion from personal stress connected to S₁. He finds it hard to conceive someone believing it is possible for him to put the reality at home behind him.

297. F acknowledges occasions of deep concentration which temporarily eradicate thoughts of his son at home but he finds it troublesome to comprehend how anyone could consider it really possible for him to forget his situation.

298. M asks S₂ to move S₁'s chair back a little and then thanks him.

299. F categorizes the previous comments as trite.

300. When asked F freely admits to moments of anger to which M adds it is quick to surface.

301. F attributes controlling himself and not talking about S₁ with helping him manage his anger. Strangely, few people ask of S₁ and they tend to be outside his social connections.

302. F says that most other questions involve insurance money. The most common question asked is about insurance money. M agrees. F says they want to know how filthy rich they're going to be. He says that people have this preconceived notion

303. [I: *How do you react inside to that?*] F says that he guesses he had a lot of bottled-up anger before because initially, I wouldn't believe the dreams of violence. He says that really concerned him for a long while. Now, the time has passed and now he just lets it pass. He doesn't ask any questions either. The best question is to ask "Why do you want to know?" But it angers F that people think that way.

304. F says that they (people) don't realize that the average settlement of insurance policies, but he guesses that they have an idea of the, most people basically include money like we're in the States. They watch t.v. here and get these wild notions about it. [I: *And that is not where you're at, at all.*]

305. F says that of course not, they are just worried about, if there will be enough insurance money to take care of S₁ for the rest of his life. F says that S₁ could outlive them.

306. F says they deal with that worry and they're in a strange situation that they sometimes have to think of, that it's better that S₁ doesn't. F says that as S₁'s parents, that is always, he remembers reading somewhere or hearing somewhere that the worst thing that could happen to a parent is to outlive their children. And they are in a unique situation where the reverse is perhaps the worst.

307. [I: *S₂, I wanted to ask you how your perspective, have things changed for you. Life, like do you. I know that you also wrote that yes his life is going on. You are doing things. But, it came through very loud and clear that what has happened does not leave him.*]

302. Questions pertaining to their insurance settlement are most common with a presupposition of new-found wealth.

303. I asks F how he reacts to such questions. F senses a lot of bottled up anger in the early days given the violent dreams he experienced. This troubled him greatly. Now he allows such questions to pass and refrains from questioning himself. While he has devised a reciprocal response he nevertheless feels anger just realizing the focus of some people.

304. F contends that the general public has little knowledge of the average insurance settlement often basing their information on t.v. reports based on American statistics.

305. F's major worry centres on the adequacy of the financial settlement to provide for S₁ for the rest of his life given that he could outlive them.

306. F and M acknowledge that possibility and recognize the strange situation they find themselves in where it would be better for S₁ not to outlive them. F recalls reading that one of the worst things to befall a parent is to outlive one's children. For them the reverse is true.

307. I asks S₂ to comment on changes to his life despite getting on with living.

308. S₂ says that sometimes he feels like, he keeps waiting for something else to happen because he knows before S₁'s accident there was a time when he and his friends were driving their skidoos and one of them got hit by a car and everyone thought the impossible and then the next winter S₁ had his accident and last fall a really close friend of his was killed in a car accident. And so everytime he keeps waiting for something else to happen.

309. S₂ says he doesn't know if he can deal with it, if he's able to keep his sanity or something, he's almost, he's sort of like emotional. He says he remembers last year when he was going to school and he was talking to his dad. It was stop and go on the [freeway], it was just stopped and he was just talking to his dad when they were rammed by a car and when they came home and he was talking to M he sort of just cried, like he couldn't, he can't deal with the, like he can't deal with things as well anymore.

310. [I: *Sort of, like a pile up of things too, an accumulation, for a human and for a young person who has not had.*] F says that S₂ has never had to deal with all those things before.

311. F says its tough, he understands when S₂ talks about the emotional side of it too. He says its not easy to keep yourself from being real emotional.

312. F guesses that maybe for guys too, he's older so maybe its somewhat easier for him to deal with the emotional side of it where S₂, because he's still in that age group where one is not supposed to feel pain, at an emotional level. F says he understands what S₂ is getting at there.

313. [I: *But things are changing, there's a lot more written about what they call revisioning masculinity and that its okay to be a real person.*] F agrees.

308. S₂ feels he is always waiting for another tragedy to occur. He attributes this feeling to a series of fatal and near fatal events involving not only his brother but two close friends. S₂ repeats his fear of another tragic event.

309. With difficulty S₂ states he is unsure of his ability to cope with so much. He worries if he will be able to keep his sanity. He is far more emotional now. He recalls an incident the previous year when the truck he was driving was involved in a minor accident while driving home. On retelling the story to M S₂ broke down and cried. He finds it very difficult to deal with such events.

310. I reflects on the pile up of events for S₂ and the fact of his youth. F notes that prior to these events S₂ had never had such experiences.

311. F empathizes with S₂'s concerns about becoming emotional and shares that he too finds it difficult to curb himself from becoming very emotional.

312. F speculates on the difficulty for males especially young ones who traditionally experience a need to disconnect from pain and emotion and qualifies this by sharing that it maybe easier for older men to cope with the emotional aspects. F believes he understands what S₂ is hinting at.

313. I digresses and shares some of her observations on the revisioning of masculinity and being a real person.

314. M says that's right. She adds that she thinks S₂ has seen them cry enough to know that its not a case of being (S₁ snorts very loudly) in an emotional situation like this. She means this is just a very tragic situation and S₂ has had more tragedy than most people see in a whole life. M says he's done it all in a year and a half. [I: *You are sorting it out. And you cry. if that's what one needs to do, that's what one needs to do.*] M says that that's the healing right there, that will keep one ...

315. F says that another thing that needs to be said is that the very fact that they have been able financially to bring S₁ home and look after him is very comforting. Its emotional comfort to them because they are able to do this.

316. F says that there are lots of people who can't do that and he often thinks what if S₁ had been skiing or skating or something like that and banged his head and had the same thing and they couldn't financially do this.

317. F says he thinks how TERRIBLE it must be for those parents NOT to be able to do that. He says its sort of funny that in one way to say that if it had to happen, well Thank God it was a car accident. How else would they have been able to do this.

318. F says oh well, there are people languishing away in institutions, they may have loved ones who would love to take them home but they just can't do it.

319. [I: *How do you, what has helped you get through this time so far? I was struck by how well, you have sort ed through, not to minimize anything you have told me or how hard this has been. But I'm really struck at how you are moving and doing the things that you feel that you need to do, that you want to do for your family and for yourselves. And I just wonder what has helped you get through this?*] M says that actually they have been asked, she has been asked that quite often.

314. M adds by saying she believes S₂ has seen his parents in tears enough times to not disparage displays of emotions. S₁ snorts very loudly. Rather, M is of the opinion that it is the tragic nature of the events and the relatively short time frame of their occurrence that has precipitated his uneasiness.. I reflects and reassures S₂ that in his efforts to sort things out he is doing the emotional things he needs to do which is corroborated by M.

315. F brings up another topic important to him. He emphasizes the emotional importance and comfort they derive from being financially able to care for S₁ at home.

316. F's awareness that many are unable to do the same leads him to speculate on how it would have been for them if S₁'s accident had not qualified for an insurance settlement.

317.F shudders in thinking of the plight of those parents unable to do so. He reflects on the irony of feeling grateful that S₁ was involved in an automobile accident thus enabling them to care for him at home.

318. F contemplates those languishing in institutions with loved ones willing but financially unable to care for them at home.

319. I inquires on what has aided them through this time. With reference to their written descriptions she notes that they have been able to do that which they have felt to be necessary for their family and themselves. M says they have been asked this many times.

320. F says that he thinks, he knows that M and he are of the same mind when it comes to, they both have the same commitment to. M adds that she thinks that's true and F adds to take care of S₁. He thinks that's it.

321. F says that S₂ is there too and he hasn't given them anything, any problems in the fact of the amount of time they do spend with S₁. S₂ understands, why it is. And so they haven't had any conflicts within the family.

322. F says it hasn't even though he's aware of what has changed, it hasn't bothered him so much that he doesn't have all the time with M and because its a common goal they just see that there's something that's come up that is much more important and they have that common goal he guesses.

323. M says that she thinks too that right from day one, like with S₂ too, the three of them sat down and discussed this is what we are facing, this is what we have to do. We are going to do this, we are going to do that, what do you think or why do you F adds that the communication, they made sure that S₂ was always involved.

324. [I: *Was like that before?*] M say in a very loud voice "no, hell no". [I: *It wasn't?*] M says "no".

325. [I: *and all of a sudden?*] M says that it wasn't as if, because S₂ was never home and there was really nothing, "hi S₂, how you doing S₂?" So there really was no communicating. F says that they always saw that that was the natural evolution, the boys were older and they were earning their, gaining their independence.⁶

327. M says that mind you, she and F did, F and her have always been each other's best friend. She and F could always bitch. She could always go home and bitch and F would say "work brrrr".

320. F perceives and M concurs that the primary fact is that both share the same degree of conviction and commitment to the caring of S₁.

321. F notes the absence of family conflict or from S₂ in particular with regard to the extent of time they spend with S₁. He attributes this to S₂'s general understanding of the need for their time-consuming efforts.

322. F confides that the changed nature of his relationship with M has not distressed him appreciably given their common commitment (to the care of S₁) which he perceives as presently more important.

323. M is of the opinion that their commitment from the beginning to fully and openly discuss all decisions and activities has been helpful to which F adds that they made sure S₂ was always involved.

324. When asked if it has always been like that M emphatically disagrees.

325. I queries if this came about suddenly and M states that since S₂ was rarely home, conversations were more in passing so that there was really little communication. F reports that this was acceptable to them as they took it as indicative of their sons' maturational process towards greater independence.

326. M states that she and F have always been "each other's best friend". it was always permissible to complain at home about work

327. F says they had a normal recreational time too. Where he was hunting and that and M has her keyboard, or she had her organ before and that didn't interest him but it didn't bother him either her taking lessons. M says "sorry F, it didn't bother me either" and laughs. F says that no, they've had no conflicts, he's had his time to do his thing and M has had her time to do her thing. [I: *So there was a certain amount of give and take and flow?*] F says for sure.

328. M says that actually they've been really lucky, they've had a really good relationship. She adds that it hasn't been heaven if I knows what she is saying, there have been a few pits in those cherries. [I: *Well I saw that you have been married for 25 years.*] M laughs loudly and says you know how these ... and then adds damn right, because you have a nice smile, my mother said.

329. [I: *No, but there is, there's obviously something very special that commitment I think there's a commitment that's underneath, that was always there. And that is what.*] M says she thinks I is right. [I: *Its changed its perspective a tiny bit now.*] M says for sure.

327. F points out they enjoyed their own recreational time where in each was free to pursue special interests or sports without opposition. I reflects that there seems to have been a certain amount of give and take to their relationship.

328. M confides feeling fortunate to have such a relationship adding that there have been difficulties along the way. I notes that they have been married for 25 years. M humorously attributes F's nice smile to the success of their relationship.

329. I suggests that their special commitment underlies their strong connectedness to which M agrees. I adds that while the perspective has changed somewhat, the original commitment remains and M agrees.

330. M says that the same with this, like when one sees, when they've got this going. She remembers their rehab counsellor asking her that one time. She said "I don't know how you manage to be so sane and things like that". M says that a lot of it is anger too because when it first happens one is angry that it happened, one is angry that this happened to your son, this should not have happened, you didn't deserve this and she didn't deserve this and F and S₂ didn't deserve this. She asks I if she knows what she means. One goes through all that and then the anger starts with the insurance company because right off the bat they're fighting. "we're not responsible and we're not responsible" and so its not my fault and its not your fault and then it its neither of you here and you're angry already and then that starts. Oh well, that's it. M adds that no matter how, [I: *it forces you to*] and M says to shift gears. [I: *focus on what is the most important thing*] and M and F agree. M says she thinks that's how it all started.

331. M says that they were very strong anyway and asks if I know what she means. F agrees and says that alot of things that happened, he can remember when they first suggested that they hire a rehabilitation company. Actually it was the insurance company that hired them. The girl that came there was, he thought, well here's a case that they don't know everything, if they need advice or somebody to look into things for them, they'd be there for that.

332. F says that it turned out to be the case where it was either they took over their life or NOTHING. So they had a tremendous row over that and they're gone now.

333. F says that they don't even have the benefit of a rehabilitation company and he supposes it would be nicer if they were thinking about something "what about this or what about that" and have somebody there.

330. With reference to a comment made to a rehab counsellor M reiterates her belief in the contribution of anger. She describes the process that anger takes when such a situation occurs. Initially anger centres on why this tragedy befell her son and the injustice of such a situation to not only her injured son but to all family members. Then the anger is extended to those agencies which facilitate the provision of services (insurance company) primarily because of the need to fight for their due entitlements. I reflects that the need to be proactive necessitates a reprioritization of what is important and M suggests this underlies the beginning of the process.

331. M reflects on their intrinsic strength as a family. F describes their early experiences with the rehabilitation company provided to them. Their initial assumption was that this company would serve as a resource of expertise.

332. Unhappily they learned that the service entailed a total management package including their own lives which they were forced to either accept or reject. Their decision to reject the service followed considerable dissension.

333. F notes the absence of such a service now and wonders if it might be advantageous to have someone to consult for advice and information.

334. F says that there's so much, there's resources out there alright but he sees that ...[I: *Do you access them or?*] and F says that he sees because of the case that they had, where it was either they control every part of their lives. I says it was a package deal and F repeats that it was a package deal and they could completely control them or not. That was the impression F got and so it was nothing.

335. F says they are back to where they were before, they're strictly on their own when it comes to trying to find things out.

336. M says that by the time they (rehab company) came in to it anyway, they had already bought the trolley, the versa-lift, the this and the that because she has a tongue in her face and so does F. M says that if you want to ask, you call the right person. She says that this rehab counselling gets to be a big joke. F agrees.

337. M says that besides, she (rehab counsellor) told them they didn't know as much as they thought. M adds that she was really something else and so they kicked her out.

338. [I: *You made the decision, you again refocused.*] M agrees. [I: *on what was the most important thing for you and your family.*]

339. F says that they were aware that there was, they might miss out important things and then maybe there was some expertise they should be tapping into. M says to F that they did that and there was nothing.

340. F says that they're also very sensitive about spending the insurance money too because there's alot of decades ahead and they can't blow everything on, wasting it.

334. F recognizes a reservoir of resources exists in the outside world but the situation presented to them was in terms of total control over every part of their lives and this they found unacceptable.

335. F believes they are again on their own, forced to access resources alone.

336. M notes that by the time the rehabilitation company entered they had already procured necessary equipment. She believes they are perfectly capable of investigating and procuring necessities. She considers rehabilitation counselling useless (a joke) to which F agrees.

337. Being told they lacked the knowledge they sensed they had was the ultimate affront and led to the ejection of this service provider.

338. I reflects that in making this decision they again refocused their priorities on what was most important to them and their family to which M agrees.

339. F acknowledges they were aware of the possibility of missing important resources given their decision but M testifies they found nothing in their own search.

340. F cites the need to manage and conserve the disbursement of the insurance fund given the years ahead of them.

341. F says that this rehab company was going to be very, very expensive. He says it took over their entire life and so two things, you've got to think of winning this all the time. They were aware there's rehabilitation, rehabilitation places down in the States too. But if they inquired and he knew damn well they would say to bring S₁ down and you'd be amazed at what we can do for him. They have also been well warned, as there have been lots of people who have gone down there and they come back worse or no better but many tens of thousands of dollars. In Europe as well. and they have to worry about that. That insurance money is, has a very finite end to it, and it can't be squandered, so they feel they have got to be extremely careful there.

342. [I: *Yeah, and always have your brain working.*] F says they're aware that there's a lot of expertise out there that can be bought too and in some ways and some of it angers him that they should have to buy it.

343. M adds that yes, they can be bought alright, but the way she sees it, she has not had one professional in their house and that's not to be arrogant, there has not been one professional in their house short of the physiotherapist and these work with the physical aspects of it that has been of any use to her. The nurse has been useless to her. The speech therapist is not doing anything more than M has or hasn't figured out on her own she should say. M says there's no expertise out there in that stage.

344. M says that they've got lots of, they are all very well educated and they are terrific people if you can be rehabilitated at that stage. But at S₁'s stage, there's nothing. So, you're really left alone and she thinks that is what they should go into because she knows that if they don't do something, then nobody else is going to do it for them. There isn't

345. S₁ makes a very big yawn. M says that they should get him in bed, he's been out there too long.

341. Given the finiteness of their insurance fund F worries of the need to manage it carefully and avoid squandering it. They are aware of not only the high cost of procuring local rehabilitation services but also of the need to be wary of accessing American or European facilities which promise substantial improvement but whose results may be disappointing and costly.

342. I reflects on their need to always be vigilant. F says they are aware of purchasable services but this angers him that they require purchasing.

343. M agrees with the purchasability of services but from her perspective she has yet to come across one professional outside of the physiotherapist who attends to S₁'s physical needs, who has provided anything more than M has been able to figure out. The problem is that there is a lack of rehabilitation expertise for people at the stage of S₁.

344. M acknowledges the capabilities of these professionals if one is at a stage responsive to the treatment they can provide. However since there is no rehabilitation expertise available for people such as S₁, M feels they are left alone and therefore she feels compelled to do this in that she is fully aware that if they do not do something, nobody else will do it for them.

345. S₁ makes a very big yawn to which M suggests its getting to be time to return him to his bed as he has already been up along time.

346. [I: *S₂, how have you gotten through?*] S₂ says he doesn't know.

347. [I: *You still seem to be getting on with your life, you're still connected with your family, very, very much so. You're doing sort of all the normal things.*] S₂ says that his mom and dad never really tried to push anything on to him, they always sort of took it as their responsibility, they never tried to make him, whatever happened, like take on any special responsibilities for anything. He says its, he doesn't know, an inner self or whatever one calls it or whatever goes on. (inaudible)

348. [I: *Do you feel you have the support of your family?*] S₂ replies that yes he feels closer to them now and adds that there was a time there, just after his friend's accident when he would rather be there with his parents than out with his friends.

349. [I: *Do you think that's for all of you, that you'd rather be together than you know out even for a little bit.*] M says oh yeah, she hates to go out to shop for the day. She does that only when she absolutely has to.

350. F says that he has to say that for himself that they were just last weekend when they brought S₁ to Bayshore again. M states that S₂ could not go because he had to go to ??? F says he's not sure if he's ever been in a place like Bayshore or certainly never went grocery shopping but now he sort of looks forward to it, getting home and bringing S₁ with them and taking him out. F says that strange as it may seem he is beginning to appreciate shopping more than anything, but mostly because its an outing with S₁, joking aside.

351. [I: *Doing the best for him, doing something different that may.*] F adds that's a real need, to know that he is doing something to help. M says that S₁'s friends don't come, the fact is the families never come. They call once in a blue moon but that's about it. And when they do come they are useless anyway, so they don't

346. When asked how he has managed S₂ indicates he does not know.

347 I points out that S₂ seems to be getting on with his life, he remains connected with his family and is involved in age-appropriate activities. He says he has never felt pressure from his parents to take on any special responsibilities Rather they shouldered those responsibilities themselves. S₂ tries to articulate something about an inner self.

348. S₂ feels closer to his parents now. Shortly after the loss of his friend he actually preferred to be with his parents than his peers.

349. I wonders if they all prefer to be together rather than out for a little while on their own. M believes that is true for her adding that she shops on her own only when absolutely necessary.

350. F now looks forward in anticipation to taking S₁ out to the large shopping complexes unlike before when he scarcely remembers even entering such a place. He considers it strange that he now appreciates the possibilities shopping offers them as a means of providing S₁ with an opportunity to get out.

351. The primary need is to know that they are doing something to help S₁. M shares that friends and families never come to visit. They may call occasionally but that is the extent of their contact. On the other hand M considers them of no use even when they do come.

352. F says that everybody else's life goes on and M agrees. F adds that they can't really expect other people's lives to change. It just goes on.

352. F recognizes that everyone else's life moves on and they do not feel it appropriate to expect others' lives to change. The fact is that life just goes on.

Family Interview 2

Code: F - father, M - mother, S₁ - injured elder son, S₂ - younger son, I - interviewer/researcher.

Context:

Two weeks have transpired since the first family interview. As the camera is being set up, F is talking with S₁, and has his face close to his, hugs him and kisses him and tells him he is going to be a star, referring to the camera. M is speaking with S₂ and they are talking about household matters. F sits down and I asks S₂ if he can check to make sure the camera is on. As the interview begins S₂ is sitting at the corner of the table between F and M. F is between S₁ on his right and S₂ on his left. S₁ is in his large wheelchair, partially sitting up. He is well cushioned by pillows. His mother has started a drip of fresh juice for him. S₂ seems quite lethargic throughout the interview, often has his head down and his voice is low and raspy. He seems tired. The parents are quite animated at times. They seem to have no difficulty sharing their ideas.

Throughout the interview all participants are respectful of each other, taking turns and apologize when they interrupt. At times they all talk at the same time especially M and F, but this is usually when they are excited about the topic and want to share their views.

* Indicates that person has responded directly to a question or reflection by I.

Meaning Units:

I: *There's some questions that I want to ask after, about how you see each other. To see how things have changed between you. But, what I'd first like to ask is uh, if there is any follow up from the last time (interview), what we talked about, certain things that came up that you'd like to talk about more about or you think is important.*

Transformed Units:

1. M says no and continues that other than the fact that since they last saw I there has been a lot of nonsense that came up, about the Gevity (special liquid nutrition) and that kind of stuff. And she guesses that it gave them, as she had mentioned the last time she was there (she corrects to say that they live there) that they were handling it and how come they were handling it so well. M says that it's funny because after they met with I before, all these things came up with the Gevity and it's amazing how quickly anger is at the door. [I: *It came back again.*] M begins oh it's and everyone starts talking at once and F continues that they're not talking, because they (the government) were just talking about cutting back on the extra cost of Gevity, they're talking about big bucks.

2. F says that the instant anger, you see is, "why do we have to be going through this again, this non-stop fighting?"

3. F says that something that M called the newspaper columnist and he said to her that he wanted to hear more about this (the Gevity) but right now he didn't think she was angry enough.

4. F says that this made him mad because they have, they have to keep a lid on the anger. They can't live the next 10 or how many years constantly worked up and angry all the time, because they just won't survive.

5. F says they have to just be, they have to be prepared to fight and they have to be, to try to stay cool all the time. So they try to keep a lid on the anger.

6. F says they went through a lot of, a long time of sleepless nights due to the anger and as soon as they close their eyes all the things start eating at them, working at them and they can't survive that forever, you know. So he says they try to keep a lid on that.

7. [I: *That was, this is what I want to hear about. How did you, what I was thinking about your role, how did you get to here? What happened?*]

1. M gives an update on the funding cutback of the nutritional diet required by S₁ and with reference to the positive affirmation for the family's ability to transcend the givenness of their situation, she shares how quickly anger returns in the face of adversity. F corroborates with M and qualifies that this time the adversity is in terms of the large amount of money involved.

2. The sudden reappearance of anger catalyses F's vexation concerning the necessity for no-stop fighting.

3. F refers to a conversation of M with a media person who indicated interest in their funding plight but urged increased priority to mobilizing stronger anger.

4. This comment vexed F further in that he fears their inability to withstand such highly intensified and mobilized anger on a continuing base and he therefore maintains their need to control their anger.

5. They are required to be both prepared to battle the enemy in the outside world yet also to remain at all time in control.

6. Having endured many anger induced sleepless nights, F realizes the impossibility of withstanding such an existence over time which leads him to endeavour to maintain control over the anger.

7. I affirms that this is what she wishes to explore and encourages them to explain further.

8. F says he thinks the secret to it is the initial funding to get the renovations done and get some sort of service for S₁. Once these things started to happen and they saw where, he thinks there was ahh, that itself helped too because it seemed like something was happening, like they were demanding this and things were happening and that helped.

9. F says that the instance some small little thing, that starts to get out of their control again and they have to get back in, and shaking people (like) why are you doing this, then you see the anger starts coming back.

10. [I: *So the anger seems to be connected with the control, the power and control.*] F says that right, exactly. M adds that they knew that they lose a bit more because they've already lost control to begin with to which F agrees and M continues that there's nothing they can do about it. M then says she's sorry to F, she did not mean to interrupt.

11. F says that no, as long as they can see that things are being done, then that helps a lot. He says they're sort of willing to do what, their part (S₁ snorts loudly). A lot of things get out of their control and then people start fighting back. Then all the anger comes back.

12. [I: *I was wondering if, when this business about the Gevity and you start, you know in a split second it twigs that ... I have to fight again. If its because it reminds you or it puts you instantly back to that time where the initial time when you realized.*] F says oh yeah, all the other things, all the other things that they've sort of got a lid on start coming back. Its not just, its not just the fight over the Gevity and that.

13. [I: *What kinds of things?*] F says oh, the attitudes of the various people coming, to the fact that nobody, you know, seems to want to do anything and uh. M says that this (refers to) was still at the hospital to which F agrees and adds that anything that anybody said they sort of, in the passing, ? sensitive things and for him anyways, they all come back.

8. F is of the opinion that securing approval for renovations and services for S₁ was the key to reducing their tension. Feeling that their demands were acknowledged and being fulfilled helped.

9. However, the instant they sensed a lose of control and the need to resume their pressure tactics, then the anger begins its return.

10. I's reflection of the connection between power and control is confirmed by F while M adds that there's nothing one can do about it.

11. F repeats that seeing action helps significantly and they are willing to do their part but when things get out of control, the need to react re-emerges along with the resurgence of anger.

12. I wonders if the resurgence of anger arising from the funding conflict over S₁'s nutritional diet is related to their initial experience of realizing the need to do battle. F agrees and adds that often other things previously under control also resurface.

13. When queried, F includes individual attitudes and the fact that while at the hospital nobody seemed interested to assist. Any little thing even in passing has the potential to reemerge.

14. [I: *How is that different from before. Do you think that the, before S₁'s accident, before you had to learn about being mobilized and getting as much as you can.*] F agrees. [I: *Did you still remember the omissions of other people then or was it easier to sort of let it pass and forget about it. Whereas now its critical issues all the time.*] F says that that's right and he gets pretty angry pretty quick again.

15. F continues that there's one of his, as a matter of fact its their union rep at work who made some reference to an elevator which was to be put in at his work to help disabled to get up. And he (the rep) was complaining that they didn't get raises in the government anymore and he brought up the issue of the elevators. The fact that they would spend money on an elevator for disabled people to come into the building and he said that there's a ramp at the shipping room, the door at the back. And F says that even something like that welled up inside of him because he knows his union is always talking about helping the disabled and stuff like this. And here was his union rep making some reference to the fact that they would spend money putting an elevator in. F says that he (the rep) might have to pay the price for that (remark) cause next election he just might be there and ask him what he things about things like that.

16. F asks if I know what he means because he feels like he's got to hit back at people all the time and if he (the rep) wants to make a comment like that, well let's see.

17. [I: *You want them to be more responsible.*] F agrees and adds that even though its, he does not use the elevator and S₁ will never use the elevator, he feels a sense of others who might want to, he feels that.

14. F agrees with I that the past differs from the present in that they had to learn how to mobilize themselves and maximize resources and also that the omissions of others were more easily overlooked or forgotten whereas now everything is potentially critical.

15. F illustrates this by relating a work situation wherein the union representative questioned the priority of installing a formal building access accommodation for disabled persons given that accessibility was already possible through a freight entrance and salaries had been frozen. Even such an indirectly related incident precipitated a resurgence of emotion in F as he realized the irony of the representative's statements and the general union policy endorsing the rights of the disabled. F indicates that he may initiate consequences at a politically lucrative time

16. F asks for understanding. He indicates feeling strongly compelled to retaliate such comments on an ongoing basis.

17. I reflects F's insistence on responsible behaviour which F adds that he is well aware of the inapplicability of this particular issue to him personally but nevertheless he empathizes with those who might.

18. [I: *Is different now?*] F asks in that? [I: *Than before, would you have been as sensitive before.*] F says definitely no, he is much more sensitive when he sees other disabled people now because he would be just like a lot of people now. He just doesn't think about these things. He has got his own, you know he has his own things on his mind and he might say, gee its too bad it never would have angered him before.

19. M asks if she may interrupt and says she thinks it would have, actually angered him because. She then adds that F had back surgery 10 years previous and he was left, when he was able to walk again, which was a big question during that time. And when he finally was able to walk he caught somebody walking behind him, imitating his walk, cause he sort of walked from side to side. And that infuriated F and stunned him to think that someone would be that ignorant. Right behind him. And she is talking about an adult. (to F) so she thinks maybe he is always rather sensitive.

20. F says yeah and M says that he is right, that its ten-fold once it happened.

21. F says that he sees that it really brings one face to face with other people's insensitivities to people who are disadvantaged and so its easier to just say yes, that people are like that and then write them off. F says that now that they're involved with the disabled, they're definitely more sensitive towards that and there's no question about that.

22. [I: *So you're in, your relationship to others how you see others, how you interact with others, it's quite different than before.*] F say that for sure, yes and M also says for sure.

18. I queries F's prior degree of sensitivity to which F affirms his increased awareness and sensitivity to disabled people in contrast to his previous way of being which he compares to most others who remain indifferent and preoccupied with their own concerns.

19. M offers her perspective that F previously would indeed have been distressed especially since his own experiences following corrective back surgery included a negative experience of inappropriate behaviour by a discourteous individual. M recalls F's indignation and anger. She believes he has always been inclined toward greater sensitivity.

20. M adds that their sensitivity is exacerbated given the accident.

21. F believes their experience has brought the general insensitivity of people to the disadvantaged to the forefront and for them it often seems easier to accept and discard such people. Their new involvement with disabled persons has unquestionably heightened their sensitivity.

22. I queries their perception of and interaction with others since the accident to which both F and M confirm changes.

23. M continues that she'd say 90% of the people they normally put up with, as they see it now, they can't tolerate for 5 minutes. She asks I if she knows what she means, like she finds that there's very few people she can relate to when something like this happens who, unless they are in the profession as such, and even then its not that certain, that unless they deal with people who have been involved in some sort of tragic situation like this, people really don't have a clue. They just don't have clue how to deal with it and how to talk to them and how to uh talk about it.

24. M says that they end up in the end, actually they don't talk about it. That's basically it. They sort of go off in their own little corner and, and they just put a defense wall up and hope they never come back.

25. [I: *What about S2, is it the same for you?*] S₂ says that well yeah, what contact he has, well sometimes people say stupid stuff like, they're not really trying to be insulting or anything and it sort of pisses him off. [I: *Give me an example.*] S₂ says that one time his boss was talking to him and he was a little angry and was saying (things) like faggot, like the guy was like Arnold Swartznegger and he wouldn't care. And he (the boss) was saying something like, something like your brother but S₂ didn't find that funny.

26. [I: *How did you respond to that?*] S₂ utters something inaudible. [I: *You wrote it off.*] M says "you idiot", referring to the other person.

27. [I: *How do you see your parents now, in terms of like the anger and uh, what I mean by the anger is that, they are quick to recognize what is sort of at stake and quite often it mobilizes all this energy that they have. Do you see a difference?*] S₂ says that he guesses that he sees them like there's more respect and he guesses they're like stronger. F states that S₂ never knew they could do it before to which S₂ says that no, he just never saw them have to fight for something.

23. M finds it difficult to relate to people given this experience and almost impossible to endure the majority of persons previously tolerated. It seems that unless individuals have had similar tragic experiences or are professionally experienced, they invariably lack not only understanding but also the ability to converse with them or about this experience.

24. Consequently, in the end the topic is avoided. They seclude themselves, erecting a protective wall and hope the individual does not return.

25. S₂ has similar experiences and finds that sometimes people express insensitive things. While he realizes there is often no malice intended he is nevertheless insensed. S₂ provides the example of his employer who equated S₁ to the degrading adjectives S₂ was expressing in a moment of anger. S₂ did not find this humorous.

26. S₂ utters an inaudible description of his reaction but he seems to indicate he shrugged it off to which his mother chastises him.

27. * S₂ views his parents with greater respect and perceives greater strength as a result of witnessing their mobilization of energy and anger when required. While F thinks S₂ did not believe in their capabilities to effect such effort, S₂ indicates that he never had the occasion to witness such efforts.

28. [I: *How do you see that, the fact that your parents fight, so strongly and so well.*] S₂ says that he thinks its impressive but he doesn't think they should have to all the time. It seems like the accident was hard enough and it seems almost like trying hardest to make it tougher for them.

29. [I: *Well, do you see that they are having to do this almost on a continuous basis?*] S₂ says that it seems like its like things are just calmed down again, like the insurance or stuff like that and now this Gevity is coming up again. [I: *So as soon as one thing gets sort of straightened out, under control then.*] S₂ adds that something else. [I: *To remind them that they've got to keep fighting.*] F. adds that's right.

30. F continues that there's something wrong with our system where we have to you know, they keep bringing up the business about the money. F says that there's every bit as much money as there ever was out there as he, its just not allocated in the right places. He says there's all sorts of construction going on some of the highways and he doesn't understand what they're trying to accomplish in that its been a whole summer and all he sees is a couple of turning lanes put in there. There was lots of money to spend on that and to keep hammering away and so many cutbacks are on social things.

31. F says that it seems like they have got to save money when they pick on the weak all the time. And that's just not fair. It seems like, well, lets see now who's going to hurt us politically most, you know, well we can't touch them so lets pick on the weak.

28. * While impressed by his parents' ability to effectively battle for needed services, S₂ regrets the ongoing nature of their struggles. He considers his brother's accident sufficiently exacting but senses the ongoing challenges as almost intentionally creating even further difficulties for them.

29. * From S₂'s perspective, it seems that as soon as individual challenges abate, new ones emerge. I suggests the purpose seems to be to remind his parents of the need to continue their efforts to which F agrees.

30. F attributes a flawed system when the centre of attention rests on money. From his perspective financial resources have remained constant but are not allocated judiciously. He cites the recent appropriation of resources for roadway renovation to the exclusion of social services.

31. It seems to F that the weak are singled out to carry the brunt of money saving efforts which is not fair. He speculates that decisions are made with regard to avoiding political retribution which leaves the weak in a vulnerable position.

32. [I: *I get a sense that you're able to see, in sort of an ethical way.*] F agrees. [I: *More acutely than before. What is right and what is wrong.*] F says he thinks and [I: *Whether this has to be done.*] he says that's the big thing, like he has said to M, you can't. Specifically about the euthanasia issue, you can't argue with some people because its a moral issue. And if you see things in terms of morality, then there's no point in, you're not going to persuade somebody who doesn't, that their life they're into certain moral values and they're just not interested in, its the morality of it.

33. S₁ snorts loudly.

34. [I: *This euthanasia business, that we mentioned before, this is really almost at the heart of it, is it not?*] F says it is. He says they see alot of danger in, if it becomes an accepted practice of assisted suicide. Then there's no question in his mind that pressures will be on all those people who. If people think its strong to end your life prematurely, then what does that say for the rest, that means that they're weak.

35. F adds that he was listening on the radio and he can remember this before our last conversation and it was just interviewing somebody who's involved, he thinks there was AIDS or something like that and the referred to the Supreme Court decision which was a 4-5 decision and referred to the 5 judges who voted for assisted euthanasia as the strong ones. F said he said well talk about perverted reasoning, it means that if you are for the killing side you're the strong one. Like it can only mean that those of us who are against that are weak.

36. F says it brings back to the fact that they've been accused of being selfish (in the fact that) to which M says that really hurts and F says it more than hurts, it makes him angry thinking about it because its twisting things around.

32. I suggests F is now more perceptive to what is morally appropriate. With reference to the euthanasia issue F says that he is aware that because of its moral nature, it is impossible to discuss it with certain people or to persuade those who have different moral values.

33. S₁ snorts loudly.

34. F agrees with I as to the centrality of the euthanasia issue for them. He perceives it as potentially dangerous especially if aligned with assisted suicide. He believes it inevitable that pressure will mount on certain people. He wonders if ending one's life prematurely is conceived a sign of strength, then will those not in favour be considered weak.

35. F recounts a radio discussion which characterized the deciding judges on the Supreme Court as "the strong ones" for their endorsement of assisted euthanasia. From F's perspective such reasoning is perverted in that killing is construed in terms of strength while those in opposition may be seen as weak.

36. As well it reminds F of accusations of selfishness which not only hurt but angered him, in light of the distorted thinking.

37. F says that there's another in the same interview that talked about uh, one woman mentioned that the way she sees things she would have less rights than animals because we can put a sick animal down. And now we can't put a sick human down. Therefore animals have more rights. Well from his way of thinking, at least we have more rights than animals because we can put them down. F means, he just sees it the opposite way around. But she sees it as animals have more rights because we're allowed to kill them but he said to M in that case if you expand upon that, well then we have less rights than animals because there's a hunting season on animals. There isn't on humans, so we should really get after Natural Resources and set up an appropriate season on us, so we'd have as many rights as they have. M says yeah but and F says its twisted logic.

38. F adds that it angers him. He feels like hitting people when they use twisted logic.

39. [I: *Was this a surprise to you? That somebody?*] F says that well this is part and parcel of this because they, never had to deal with this kind of thing before and now they're face to face and every time someone says something like that, now he just can't say, he just can't shut his mind off and stupid and forget it and later it would be out of his mind. Now it stays with him all the time.

40. [I: *Was it a surprise that somebody decided to mention this to you?*] M says "Oh God yes". [I: *Like it just came out of left field?*] F asks if she is talking about the euthanasia issue. [I: *Yeah, thinking not specifically about S₁ but the fact that you're in this very difficult situation, and people start talking about euthanasia.*] M says yeah, she thinks.

41. F says that more than the surprise, it seems dangerous because this has all come along at a time when money is tight and he can see how its an easy out.

37. To extend the twisted logic of such thinking F refers to an argument proffered suggesting greater rights for animals in that they may be relieved of their suffering whereas this is not possible for humans. F points out the hunting season which also legitimizes animal killing and suggests that to equalizes human rights with that of animals a hunting season on humans ought to also be established.

38. Such thinking angers F to the point of wishing to strike out at those engaged in such endeavours.

39. F considers coping with the euthanasia issue as part of their burden in that they never had to attend to such issues in the past. Now they are repeatedly brought face to face with this issue each time even remotely related issues arise. F finds it impossible to ignore or disregard it and it remains with him all the time.

40. M agrees with I as to the surprise and unexpectedness of this issue. Though not thinking specifically of S₁, I wonders at the effect of discussions on euthanasia given their most difficult situation.

41. F considers this topic more dangerous than surprising particularly since financial resources are diminishing /shrinking and this might offer an easy way out.

42. F continues that now people are saying, well we have to cut back on the deficit and here we are, we have all these old people and disabled people eating up our money. You know that I could pay less taxes and have another car and TV in this house if I didn't have to look after these people you know.

43. And F says that he thinks its a very, the young generation excuse him, coming up is very, very selfish. He says that they're sort of in between. He thinks, if we notice the people who seem to be most, or the group that seems to be most in tune with caring about other people are old people, because they come from a different generation with different thought.

44. F continues that as we're going to be left with the generation that just doesn't give a damn about anybody else. Its a struggle to survive and its unfortunate that you got hurt but too bad, don't ask me to spend money on you.

45. [I: *What about for you M, the euthanasia, what does it trigger in you.*] M says that it all started with this [Talk] Show that they went on. And when they realized what the topic of conversation was, she can remember going back to the hotel that night and she doesn't think F and she slept 5 minutes.

46. M says that for three days, they came back on a Wednesday, she'd say till the Friday, she was inside out. She couldn't put a lid on where, what it was about it besides the fact that the topic would make her sick. And it made her realize by the third day, she felt sick to her stomach literally and she thinks she actually vomited at one point.

47. M says that finally it was when it hit, Friday. That's it, we're talking about a human life.

48. M says that here were these young people and she apologizes again to S₂, but they were young. She says they are being taught this that euthanasia its a good thing because just wait when you get older, you're going to have to pay to take care of these people.

42. F worries that the need to decrease the deficit may precipitate attention to the resources consumed by the elderly and the disabled. He fears some may consider the possibility of reduced taxes and procuring material goods if certain populations did not require financial support.

43. F is apologetic but nevertheless considers the younger generation as selfish, whereas his age group is in between and only the elderly seem genuinely attuned to caring for others primarily due to their different generation and way of thinking.

44. F fears society will be left with those who care less about others and they may refuse to fund those in need because of their own financial difficulties.

45. When asked about the effect of the euthanasia issue, M explains the origin of their troubles occurred when they participated on a TV talk show. The distress resulting from their realization of the true topic of interest precipitated a sleepless night

46. M was seriously distraught for several days but still unaware of the origin. Her awareness was initially limited to feeling nauseated each time she considered the topic.

47. Finally it hit and she realized the topic with the reality of human life.

48. Apologizing to S₂, M identifies young people, since the majority of the audience was young, as the group being taught the merits of euthanasia as a means of reducing financial support to those needing care.

49. M says yap, yap, yap, and she was thinking that and looking at their son and she was thinking, "I would die for that kid or for S₂".

50. And M says that those young people there were thinking you should just snuff it out. [I: *It's so easy.*] M repeats its so easy and says you just go (snaps fingers) like that.

51. F says that except though, the [Talk] Show, that was just uh, look at it as part of educating. He says they were duped into that show. That was not what they were. [I: *Was that the first time that that idea even crossed your mind?*] M says it was brought to the forefront and F says he would say so. Everybody talks together.

52. F says he thinks the Sue Rodrigues case goes back before that time and he doesn't think it ever. [I: *But you never.*] F says they never related it to their situation and it was only on that show that it came up to the forefront and aside from the fact that that's not what they were there to talk about. They never thought of that as an issue that affected them to which S₂ says yeah.

53. F says it is all part of their education. He says that they become a little wary after awhile and now, before they would ever speak, talk to a reporter or think about going on that type of show like that again, he's be much more careful about, be careful about not to get used.

54. F says if it happened again today, with having been burned and all this sort of stuff, they would have seen him walk right off that show. At the time they were sort of , you know. [I: *You were unassuming.*]

55. [I: *Like, am I correct that before the accident life was sort of everyday.*] F agrees. [I: *You know, you were unassuming but now, you have to be hypervigilant.*] F says yes, exactly. [I: *Always are on guard for, you know, what is being said or what is expected of you.*] F says yeah, that's right.

49. However, hearing all this and looking at S₁, M realized she would die for him or even for S₂.

50. M remembers that the young people (on the show) advocated simply ending life, which could occur as easy as snapping one's fingers.

51. F now considers their talk show experience as part of their education. He believes they were duped into appearing on the show under false pretenses. When queried if this was the first encounter with this topic, M says it simply brought it to the forefront but F confirms this for him. Everyone talks at the same time.

52. F believes a celebrated assisted euthanasia case predates this occasion. However, they never related such an idea to themselves and only on that talk show did it come into prominence despite the fact that they did not believe they were invited for such a purpose. S₂ agrees with them.

53. Because of their experience F believes they are now more mindful and would be more cautious about disclosing their situation to any media personages. They would definitely be more vigilant as to the possibility of misrepresentation.

54. F asserts that should a similar situation ever arise, he would immediately remove himself. He believes they were basically unaware and I adds unassuming.

55. I reflects that prior to the accident their life was ordinary and they were basically unassuming while now they must be always on guard, hypervigilant to all that is said or expected of them. F agrees.

56. F says he also feels that he'd like to be able to say his piece to people because if you don't get as many people as you can on the side of the disadvantaged, then nothing will ever change because he doesn't think most people stop and think about it.

57. F adds that if one talked about, because the euthanasia people talk about it in terms of being DIGNIFIED in somebody's life and they see that that sounds good on a strictly humanitarian basis. [i: *An abstract basis.*] F agrees.

58. F continues why would you have somebody suffer. He says they don't stop and think, well first of all, who, just because somebody's dying of Lou Gehrig's disease of AIDS or whatever it is, he doesn't see that as, what's undignified about dying. He says he means that mother nature's got all sorts of ways to end life and we all have to die sometime. He says there's lots of ways to die and he doesn't see it as somebody slowly wasting away as being undignified. He does know that they don't have to suffer and they'll only see it as undignified if we tell them its undignified.

59. F continues, you know, you brainwash people into wanting to end their life because we tell them "you're a drain on our precious resources". You know what a rotten way to have to die. They start to think that way and they're at a great disadvantage emotionally too and they're easy to sway you know.

60. F says that they don't have to die in pain, nobody has to die in pain. There's no, he has no moral dilemma to see somebody given enough pain-killing drugs in their last days that in actual fact, that maybe those drugs hasten the end, and he doesn't see any moral dilemma there. He doesn't think anybody has to through pain.

56. F feels strongly committed to speak out for the disadvantaged. He believes that unless the support of as many as possible is secured change will not be forthcoming since he is of the opinion that most do not even think about the disadvantaged.

57. F recounts how the euthanasia supporters construe euthanasia in terms of being dignified and sound on a humanitarian basis to which I adds in an abstract sense.

58. While the supporters of euthanasia believe it is a means to avoid suffering, F wonders how dying can be construed as undignified in that it is a natural process and everyone dies at some time. F is of the opinion that dying no longer has to include suffering and more importantly he believes that dying is experienced as undignified only when designated as such by others.

59. F is convinced that people are brainwashed into believing they are a drain on public resources and therefore their death would be advantageous. F believes this a terrible way for a person to anticipate death. He notes their greater disadvantage and vulnerability to such thinking.

60. F firmly believes no one need suffer physically during the final stages of dying. He has no moral reservations as to the administration of potentially lethal doses of pain-killing medications at this time.

61. [I: *Was S₂ involved with the Talk show at all?*] M says no. [I: *What, had this, had this crossed your mind. Are you as concerned about this aspect as your parents are?*] S₂ says he didn't really think about it before. [I: *But now.*] S₂ says that after the show it was kind of stupid, like he didn't really feel this strongly about it because if he. He says he was kind of stewed because some girl came up and said something to his mom and dad about "how can you go against S₁'s wishes or whatever, like, if he wants to die or whatever how can you go against him.

62. S₂ says he was thinking well that means basically like suicide and okay he'd like to know how she'd feel if one of her best friends came up and said I want to kill myself because in that case whatever her problem is she doesn't want it and he'd like to see if she'd say "well okay". He then says twisted logic.

63. F says that S₂ mentioned this because S₁ had mentioned at some point before this accident, they were looking at something and S₁ had said "I sure wouldn't want to end up like that, I'd sooner be dead".

64. F says that people twist that to say well now we should give him his wish. But then they've all said that.

65. F says he can remember at the end of the [Talk] show she asked for a show of hands, which one of us (the audience) would like to end up like that and she said she knew she wouldn't want to end up like that. And F says that he wishes to this day that he had jumped up and said and thrown his hand up and said "I wouldn't want to end up like that either, what is the point of the question.

66. M says you idiot, what a stupid question, who the hell. F adds that (though) some people do so, how is that an argument for ending life. He says that none of us would want to be there. S₁ snorts loudly F adds that you know its just a silly question.

61. S₂ was not involved with the TV talk show and had never really thought about this issue before. Though not overly concerned about this following the show, S₂ was nevertheless upset by a comment made by a young person to his parents questioning their going against S₁'s wishes.

62. Equating her statement with the notion of suicide S₂ then wondered if this person would herself respond in agreement to a personal friend contemplating suicide. S₂ considers this twisted logic.

63. F explains S₂'s example since S₁ had in fact on a past occasion indicated his preference to be dead rather than to live while severely impaired.

64. F believes others distort S₁'s earlier statement so that they should now feel compelled to comply with his wish. F believes most people have also uttered such statements.

65. S recalls the show moderator asking the audience to indicate who would be interested in living in such a manner. F wishes he had overtly expressed his own opposition to such an existence but qualified it by indicating the ludicrous nature of such a question.

66. Recalling the emotion of the situation M makes several degrading comments. F wonders how agreement with such a statement provides a rationale for ending a life. S₁ snorts loudly and F again indicates the inappropriateness of the question.

67. M says that because if we all had a choice, lets face it, we'd all want to die in our sleep. Wouldn't that be great, like your grandma did to which F agrees.

68. M asks if I know what she means. She says it just so SICK, its so sick it makes her sick and she puts her head in her hands.

69. F adds that alot of their focus now, that they're on the euthanasia bit, it seems that everything seems to focus on that . But also for very good reasons too. Like he said too, he can see problems down the road trying to get any help from the system if it becomes accepted you know because they'll just say that why.

70. [I: *Does it scare you? Does it scare you to think about, that we, only in our society we are actually talking about things.*] F says that he thinks they're scary, yeah but he doesn't think its unusual. He thinks every great civilization, its just a repeat of history. He says he means every civilization degenerated and at some point down the same type of road. He says they're just going the same way.

71. F continues that we can isolate it and some of the burden is off us. You know, he can see alot of burden, society'll wash, continues to wash its hands but hopefully they'll isolate him (S₁) providing they live along time. He says that not knowing into the future and how things will end up, it worries them that, if they loose control. [I: *The control.*]

72. F says that if M can't stay in charge and look after him (S₁) that's worrisome, that seems like so far down the road. [I: *Well you'd like to think that its so far down the road.*] M says that right and she gets to a point till she realizes that she's going to worry about this. Like she used to, that was foremost in her mind all the time. Even yesterday she was in the truck and driving on the highway and she was thinking subconsciously, she was going "Just let me get there and let me get home okay". She says she does it every time she gets in that truck.

67. M is of the opinion that everyone would choose effortless death given the choice and F agrees.

68. M requests understanding and is overcome with emotion as she contemplates the perverseness of the statement.

69. F recognizes that presently euthanasia dominates their attention primarily due to F's fears of future difficulties procuring assistance from a system that promotes such activities.

70. * F suggests that while he finds such a notion distressing he also recognizes that our society is no different from other great civilizations in the past who also moved in the same direction.

71. F believes that if we isolate this notion then we will be temporarily relieved of this responsibility. However with an increasing burden F believes that society will wish to be relieved of this responsibility. F hopes they will be able to protect S₁ which he realizes will be contingent on their own existence. Given the uncertainty of the future they continue to worry over loss of control.

72. F worries that M might not be able to continue to care for S₁ but it seems relatively far into the future. M agrees with I that they would like to think it is far into the future and she shares her almost constant worry over this exact concern. When away from home on her own she always worries that she will return home safely.

73.1 [I: (referring to her own experience) For me, its wondering when I come home, could it happen again that somebody would be there to say X has happened.] Both F and M agree. [I: Especially if I'm out at night and I'm coming by myself. I wonder.] F and M agree again. [I: What if? I feel it., touches her abdomen.] M says everytime she goes out the door, everytime S₂ goes out, she waits for the phone call.

TECHNICAL BREAK

74. I: There are two things that I wanted to ask about. And one was, the space in between. From there to here (gestures with hands). As you said to me on the phone, that it hasn't all been like this. You know, that, how you've managed to get through and what's been a help to you or what you've had to face. There's that but I also want to ask about how you see each other, now, from before.

75. [I: Like how do you see, say for you M, how do you see F, have you seen changes in him, things have gotten more difficult.] M says for sure. But she thinks F was always a very intense, very serious and on the other side a very, she guesses not on the same side, a very sensitive man to begin with. And he never did anything half assed if I knows what she means. It was either he did it completely or he didn't bother. And F is not a chit-chatter in a social environment, he's just, things that are important to him are very important to him.

76. M says that when this (the accident) happened it was magnified a hundred times over. The sensitivity and the, and the, she means she always knew how much his boys meant to him. They didn't know it because kids are kids and they think their parents don't really care about them but they do. And M says she knew that of course and as she said everything was intensified, magnified a hundred times over.

73. I empathizes by sharing her own similar experiences which centre on the fear that another mishap will befall her family while she is away from home, especially at night. I says she lives with a constant "what if" feeling and M shares that for her its waiting for the phone call every time a family member goes out.

74. I indicates that in this section of the interview she would like them to focus on how the family has transcended the space from the time of the accident until now, including the struggles and what has helped as well as how they now see each other as compared to before the accident.

75. * M sees definite changes in F since the accident. However she describes him as a very serious and sensitive person even before the accident. All efforts were thorough and never incomplete. Socially he was not superficial and once he designated something as important then he maintained that belief.

76. According to M, F's way of being, including his sensitivity, was profoundly magnified following the accident. In particular, though his sons had little sense of this simply because they were young, M fully realized the importance of F's sons to him.

77. M says the worst of it was watching through, in the hospital setting, at the way F was treated so indifferently, like "why are you here?" and "just go to work" and stuff like this.

78. M says she was really taken back by how vic!ently he reacted to it. And she knows there were instances before the accident where certain circumstances would come up and she always thought and then she'd wake up all of a sudden and he'd be up. She asks I if she knows what she means. Stewing over it and she uses that term stewing over it but thinking about it and stuff like that.

79. M says that when all of this happened it created alot of sleepless nights and a lot of worries for both of us. But for F it was almost worse. Because men are taught, you know the old way of, you're there to provide for your family and you're there to do that and that.

80. And M says she saw him so stripped of that control and so in that sense it was very difficult. Because she had her own thing to do with it too, so it didn't affect their relationship in a sense between them.

81. M says it probably made it (the relationship) stronger because they always had a very strong bond. F was always her best friend. And she was his. And so in that sense it rather, it didn't split them, it just brought them closer and their goals were very much the same.

77. For M, witnessing the lack of compassion by hospital staff for F's concern as well as the condescending attitude towards him was the most difficult.

78. M was struck by the intensity of F's reaction to this treatment. However she was aware of his previous propensity to fret (worry) in certain circumstances.

79. While both parents were distraught with worry, M considers F's experience to have been almost more distressing in that men are taught (socialized) that they must provide for their family in certain ways.

80. M perceived F as being stripped of this control which made the situation extremely difficult (painful) given that she too had serious concerns. In that way, their relationship was unaffected.

81. M contends that this event probably made their relationship stronger. From the beginning they had always shared a strong attachment being each other's best friend and now this event seemed to bring them even closer together in part because of this shared goal.

82. M says she must admit that she, there's a part of her that was a bit surprised that F was as adamant about it as he was and as his goal was so much like hers, they were so pulling in the same direction that she was. Like she said, a very small part of her was taken back, it was that strong in him because sometimes you have things that you just take for granted, you don't think about. F's was the same reaction on the Shirley Show you know. You don't realize how strong it is within you to protect and take care of and survive. As it was and for him this certainly came up in that sense. But it was good too because it cemented it even more and she asks if she knows what she means.

83. M says that because it could have been the other way. You know, one of them could have been against what they did and they would be fighting each other left right and centre. But, so that was the one change she certainly saw and it was a big, a big, although it wasn't really a change, it was just a magnification of his actual character is what she saw.

84. M says that Thank God too because she doesn't know, that if she hadn't had that kind of seriousness, that kind of push she would have still done what she had done but it was sure great to have F to lean onto and to back her up too because its a tough thing to do together never mind do it alone. She says you see, that was the most of it there.

85. M adds that there was alot of bitterness in some instances like her own family physician. The attitude was, well don't make this a crusade M and don't, you have a mother to think about. don't let this be a crusade because he (S₁) will get better whether you're there or not, sort of attitude. And then F going in and him (the doctor) saying "what's your problem F?" F couldn't sleep at night, he had violent dreams and stuff. and F said "well I can't sleep and I need something to help me sleep even if its artificial, just something" (the response was) Oh what are you trying to do build a dynasty? My God.

82. M admits to surprise at the similarity of F's goal to hers, in that they both seemed to be pulled in the same direction. Emphasizing the strength of his concerns she believes that often these feelings are taken for granted so that individuals do not realize the strength of their concern and instinct to protect and survive. However M believes this was good in that it helped cement their relationship.

83. M is aware of the possibility for an opposite situation where they opposed each other and conflict became the norm. When considering this change, M reflects that in reality it was more a magnification of F's actual character.

84. M thanks God for this turn of events because without F's serious commitment she would have been compelled to do it on her own. She appreciates F's support and assistance and can imagine the stress involved if only one parent carries the full burden given the difficulty experienced when two parents share the responsibility.

85. M recalls much bitterness and gives the example of an experience with their family physician. His attitude was to caution M not to making a crusade out of this experience, to consider her other familial responsibilities and to negate any contribution of their assistance to S₁'s recovery. In addition, he was unable to empathize or understand the distress F experienced and as a consequence offered a very demeaning reply to his request for artificial help with a sleeping problem.

86. M says F walked out of there and that was the time and that's it. He's (the doctor) been written off for 30 years. He's been her physician, he delivered S₁ and S₂ for that matter.

87. M says that it hurt alot to see F, he was so victimized. In some cases M felt that F was more victimized with all of this, there really. [I: *Why do you think that?*] M says that well because of the attitude, she found of the nurses. Like she didn't say too much about it because if used to eat at F. It was almost like "really, what are you DOING here?"

88. M says it was like they understood it in her case which didn't make her feel any better because "you're just a neurotic mother" and I'm sure you (refers to I) can relate to that. You're just a neurotic mother, but its expected that mommy's going to be here with her little baby.

89. M says that F there is going "THIS IS MYSON, he's 22 years old" In the normal scheme of things he needs me. He needs a male figure in here to uh.

90. M says that what they wanted to treat F like uh "fathers don't get involved with their babies, get out of here and go to work, you know like you normally would. what's the matter with you.

91. [I: *How did that affect you?*] F says that it made him sick. He says it was so obvious to him too. M adds that they used to say to F (S₁ snorts loudly), the attitude was there.

92. M continues that it was also the attitude of the situation that he was in, their son was in. That, they were probably both wasting their time. It was more so directed at F and it made her sick because she thought what's the matter with these people, and its such a little, is it just a one sided issue here where its just women who care about their kids. Mothers who care about their kids because they carried them and so the bond is stronger.

86. F's departure concluded their relationship with this physician which had spanned many years and included the deliivery of her two sons.

87. M describes the hurt she experienced from witnessing the maltreatment of F. She felt he was more seriously victimized in that the attitude of hospital staff, nurses in particular were especially condascending in that they questioned his concern and continued presence. She said little at the time as she was well aware of F's distress.

88. M perceived their tolerance of her presence though she nevertheless felt they considered her in negative terms as a "neurotic mother" and therefore entitled to being with her child.

89. M recognized F's emphatic assertion that this was his young adult son who needed the male presence of his father.

90. M believed that the nursing staff insinuated that F should behave as a normal father, go to work and not be involved with his children.

91. * F was well aware of their attitude and it made him ill. S₁ snorts loudly.

92. M also detected a general attitude which seemed to imply that they were wasting their time. While she believed this attitude was directed more towards F it nevertheless made her not only ill, it made no sense that only women should care to any great extent about the welfare of their children despite the strength of the bond of pregnancy.

93. M says that that's not true. And all the way along they saw this. She says there's been divorces in their families too and they saw what her kid brother and F's brother and they saw how much they were sort of thrown aside all the time. For and it was always on the mother's side, well she has the children this and this that and the other.

94. M says that after a while they sort of got fed up because she lives with a husband who cares about those kids as much as she does. She asks I if she knows what she means and adds that she wanted to scream at them and say "wake up", he's just as important as she is, in some cases maybe more so because him (S₁) and F had become ...

95. M says that S₂ in small ways too, only S₂ was younger but it still had become that stage where they were past the father-son things and they were into "Hey Dad, you should try this, lets do this and lets do that".

96. And M says that these people just wanted to quickly throw F out of the picture and just deal with her. She doesn't know if it was because they were afraid that two combined made too much of a fight. She adds who knows.

97. M says that all she knows is that it was, THE main reason they got S₁ out of there (the hospital), so that they could have the control and they could say to them "this is what we are doing, and this is what is going to happen.

98. F adds that he felt strongly to protect S₁'s manhood, because its and they see this in old folks' homes too where the nurses and the staff talk down to these old people. Some of these, you know old folks, they went through a war and who knows what they did.

93. M does not agree and cites the example of the negative way divorced fathers are discarded and the mothers are given preferential rights to their children.

94. Over time they became exasperated given the fact that M was well aware of F's special concern towards his children. M wanted to scream at the staff and tell them to wake up, that F was as important as she and maybe even more so given their maturing relationship.

95. M describes the father son relationship as having gone beyond the father-son stage to a more mature male sharing type of relationship especially with S₁.

96. M was aware of the staff's desire to be rid of F and deal only with her. She speculates that this may have been in part due to fear of their joint strength.

97. For M this became the singularly most compelling reason for deciding to remove S₁ from the hospital so that they could have the control they felt they needed over his care and the care providers.

98. F felt compelled to protect S₁'s manhood. He cites the example of elderly people in nursing homes who are talked down to despite the fact that they have made contributions possibly even risking their lives in the service of their country.

99. [I: *Is this something new for you F, like had you always, had that been there before but now its?*] F says he was, never really sort of thought out as his role as a father. He, he hates to call himself a bit of a chauvinist. He honestly things he is. But he has to admit, he's more proud that he has two sons than if he had two daughters or one was a daughter. He can, he can't help that in himself. When he saw boys were born, he was more happy because they were boys. He has to admit that.

100. F continues that he doesn't put women down or something. He sees a lot of women have done incredible things, like he would be the last one to step in the way of anyone to pursue whatever she wanted.

101. F says that he can't escape that feeling inside of him. These are his sons.

102. [I: *What I wanted, was that you had mentioned about the older men. Saying that they had been through the war, they had done certain things which naturally would mean that we were children with a certain amount of respect (for them) and yet they become infirmed or disadvantaged as you say and we relegate them to.*] F adds that they are children again where they're children and that they happen to lose bladder control and we give them a slap on the wrist and we say "you bad boy" and F feels this need to protect his son from that.

103. [I: *Is that new?*] F says that he never had to be. [I: *Did it just come naturally?*] F says he guesses that the basic instinct surfaced, he didn't have to before because he never had to worry about his boys staying their ground. He never had to worry about, they were all boy.

99. * F reflects that previously he thought little of his role as a father but now considers himself somewhat of a chauvinist in that he was singularly proud having two sons rather than daughters or even one son and one daughter. He feels unable to help his feelings and admits to the sheer joy at the realization that his children were sons.

100. F is not against women nor would he hinder their progress. As well he recognizes their invaluable contributions.

101. F says he cannot escape the pride he feels inside, these are HIS sons.

102. I returns to the issue of the older men who served their country, who are given a certain amount of respect but when infirm or disadvantaged are relegated to a care facility. Aware that they are often scolded for natural bodily malfunctions F is intent of protecting his son from this.

103. * Prior to the accident F's boys had always stood their ground so that such a stance was unnecessary. This stance (of heightened sensitivity) emerged naturally as a basic instinct coming to the surface.

104. F continues that he was really proud of them (his sons). He was proud even though its a worry and he was glad they were motorcyclists. F was a motorcyclist also and as a parent he could sit back and think gee I wonder if my parents worried about me every time I was blasting off on a motorcycle and just seeing how fast I could make it go. And now F says he worries about that but there is a side of him that says Thank God they are like that. That the image of boys.

105. [I: *Can I ask you how you saw, how you see M, and the changes or the things that she has had to cope with and go through.*] F agrees and says that probably for him he sees more change in the, he sees a part of M that he didn't see before that she would see in him because the burden, 90% of the burden is on her shoulders, because she is with S₁ all day long and F sees what she does with S₁.

106. F says he REALLY ADMIRES M, he feels really, really lucky He says he says this all the time "what would I do if she wasn't the kind of person she is?"

107. F says that there's really nothing in their life that ever showed him that in control, fighting side of her.

108. F says that M is a very social person, she can talk to people and these are sides of him that, she's the opposite to the way he is. And he sort of always admired her. He always wished he was more like her but this situation showed him a side of her and he doesn't know if he ever told her, he really admires her and he really feels lucky because he'd be in a terrible situation if she wasn't capable of doing what she can do.

104. F was always proud of his sons. Though at times worrisome he was especially pleased with their interest in risk-taking motorsports as he was. On occasion F wondered if his concerns were similarly evoked in his own father each time he engaged in such activities. Despite the worries F was nevertheless delighted his sons' fulfilled his image of young males.

105. * In describing the changes observed in M, for F it is the side of M unseen before, the shouldering of the brunt of the caring for S₁ which stands out.

106. F strongly empathizes the admiration he holds for M. Though he feels extremely fortunate, more importantly he worries how he would have ever managed if she had not been the kind of person she is.

107. Prior to this event there was nothing in their life together that ever showed F this in control, fighting side of M.

108. F sees M as a very social person. Unlike himself she is extremely capable of conversing with others. Having always admired her, at time wishing to be more like her, F sees a side of her evoked by this situation which prompts him to express to her directly his genuine admiration and feeling of good fortune. F is aware of the tenuous situation he would find himself in should M have been unable to care for S₁ as she does.

109. F says that he is very limited, he means he leaves there (home) every day and he can't do what she does, like all those telephone calls and deal with all those people and everything and she does it. She does a good job of it you know. And F says he tries to support her as much as he can.

110. F says that when he is there, and he wants to be there, he can't wait to get home to see S₁. [I: *To know that he's well cared.*] F agrees and says he doesn't have to worry about that.

111. F says that he sees that there is, M is so fussy you know. Sometimes it's even a frustration for him because he'll be helping her out and moving S₁ into that chair and says it's good enough, you know. She will say oh no it isn't and she'll straighten, make sure his shirt is pulled down so he doesn't have any ridges on his back and F finds it a lot, he just finds it a little annoyance.

112. M says she has to say that it happened in the hospital too one day. F said "I have to tell you this really bugs me" and M said "yeah, let me tell you something, you lie on that bed and put a little crease in it, you lie there for two minutes and you see what it feels like".

113. F also remembers when he was in the hospital too and they were, he remembers they were really good too, about every two hours they would come in and they'd change him from side to side. And F can remember that he was in terrible pain by the time that that two hours was up and being in that one locked in position. And the highlight of those two hours was when they came in there and changed his position. So F says he can relate back, he knows how painful it is after awhile to be in absolutely one position and you can't make the slightest adjustment. So he can, it helps him to understand why M does it.

109. F acknowledges his own limitations, the necessity of being at work each day precludes him doing the many tasks M accomplishes including all the interpersonal interactions she attends to. He recognizes her proficiency and tries to support her as much as he can.

110. F enjoys being home and is always eager to return home to see S₁. Though he wishes to reconfirm S₁'s well-being he knows he never has to worry about that.

111. M is exceedingly particular with S₁'s care which annoys F at times. She will invariably notice something is not quite right and is insistent it be rectified.

112. One day F shared his annoyance with M while S₁ was still hospitalized and she graphically and strenuously explained the rationale behind her need for perfection in S₁'s care.

113. F recalls his own hospital experience wherein he himself endured similar situations. Remembering his own helplessness and dependence on others to help ensure some degree of comfort helps F to now appreciate M's insistence on S₁'s painstaking care.

114. F says that M has never been through it and it amazes him that she knows either from her nursing training or because he came at the time and even though she's never experienced that pain she is absolutely religiously with S₁. There's absolutely nothing she won't do for him.

115. [I: *Is she like that for everybody else, do you know?*] F says oh for sure, yeah. Jokingly and laughing M says she just leaves S₂, he makes his own bed. [I: *So you know that S₂ is well cared for and in a way you are well cared for.*] F chuckling and joking says that yeah, he knows he's spoiled. M laughs too and S₁ snorts loudly.

116. [I: *How is your relationship uh, with M as a wife now?*] F says they don't have the same time together that they used to. They travelled together all the time and everything. He really misses that, those times together. But when he's home, unless he's outside to cut the grass or something like that, away from her like that. He really liked to take, he took a lot of, just to go and talk to her. He really enjoyed talking to her, he really enjoyed that time.

117. F says he never had any problem with the most intimate details of how they felt, like he never, he's always free and never uncomfortable talking to M about his weaknesses and M laughing says she's wasn't either and then apologizes. F says they always had the kind of relationship that they could really open up to each other.

118. [I: *Would you say that that has gotten more so now?*] F says that in a sense because M has seen him emotional where perhaps she never saw him so much so before. But he says they never got cut that deep before. It wasn't difficult for him to do that in front of her because he knew she understood.

114. Given that M herself has not personally endured such an experience F is amazed at her sensitivity and awareness. He speculates it may arise from previous nursing training or his own experience. Lacking her own experience she nevertheless is adamant about S₁'s care, sparing nothing for him.

115. According to F, M cares for all of them in the same manner. He not only knows that S₁ is well cared for, he feels well cared for himself, even spoiled. All seem to agree as indicated by the shared chuckling and joking. M jests endearingly that she just leaves S₂ and he has to make his own bed.

116. * When describing his relationship with M, F misses most their shared time together. It is different now. He really enjoyed being able to sit and talk with her and it has been hard for him to deal with this.

117. F was able to share even the most intimate of details with M. He was never uncomfortable talking about his weaknesses, nor was she. Their relationship was one where they could really be open with each other.

118. F has been more emotional in front of M whereas previously she had never seen him that way before. This was not difficult for him in that he has always known she would understand.

119. M says that there's one thing that F always said and that was from day one, from the day those kids were born and if you ever wanted to get to somebody the only way anybody can really hurt me is to hurt my kids or my family. But M says that his kids more so because they are defenceless, you know they were young and well even today so she guesses that that's and F adds that that was probably his greatest fear in life, something happening to one of his kids.

120. F says that he said it, never really thinking it would happen, but he knew that would be. For him, you talk about somebody "what is your worst fear?", like some people talk about, I wouldn't want to get thrown in a pit of spiders or snakes or something like that. That stuff doesn't and M says "neat aye?" F continues that his kids, he was really uh. He always felt that that was his horror in life, if something happened to one of his kids. And so to him it was his worst fear really.

121. F says he doesn't think he is unusual cause everybody is most vulnerable to their kids and mind you, he doesn't happen to be afraid of spiders and snakes you know but.

122. M says that its true. When you have kids she thinks you'd give up your own life for your kids. That and perhaps look, you sure as wouldn't do it for somebody else, but for your kids, you'll do anything.

119. In response M shares that from the beginning, F had always felt that the only way to really hurt him was through his children or his family and from her perspective it was through his children in that they were young and more defenceless. F adds that he believes that his greatest fear in life was something happening to his children.

120. Contrary to most others who fear serpents or insects most ,F always maintained that his worst fear and horror in life would be to have something happen to one of his children.

121. F believes he is similar to most others who also fear a mishap occuring to their children. He notes his own lack of fear of insects and serpents in passing.

122. M agrees stating that most people would give up their lives for their children, though they would definitely not do that for others

123. F says he can remember on, he believes it was Rescue 911 on TV one time before and a young girl got, somewhere down in the States and he guesses they have these drainage ditches. When we have severe [I: *We have them here too.*], a severe thunder storm and all the water runs into these big ditches. And the story about this young girl, she fell in this drainage ditch and she was getting washed down and he doesn't know if it was a younger brother (M says it was a neighbour) or a neighbour racing down and trying to get ahead of her where he could try to grab on to her. Eventually we saw that at one point she was on the other side of the ditch, holding on to something and he was on the other side and there was a tree or something sort of hanging over and he was holding onto a branch and reaching out as far as he could stretch and just trying to grab onto her.

124. F says that when he saw that, he said that's exactly the way he feel, like he is reaching real, real hard and it seems like, you know every day that's the way he feels. He's up there and stretching but he can't. He's so powerless to change what's happened and he seems to be powerless to make things happen.

125. F says he's just wishing that, to just find something that would just trigger a good conclusion for this. But all day long, all his strength is trying to reach, but he can't quite get there. He says you know he lives with that day after day. [I: *But each day you keep trying again.*] F says yeah, oh yeah, sure, he can't get out of trying.

123. F recalls a TV program presenting rescue situations. In one episode which is firmly imprinted in F's memory, a young girl was being swept away in flood waters and a neighbour in his attempts to rescue her was holding onto a branch extended over the water and he was trying to reach out as far as he could so as to grab onto her.

124. Seeing that catalysed F's feelings. Each and every day he feels that he too is reaching and straining as hard as he can, trying to reach but he is not able to. He feels powerless to change things or to make things happen.

125. F continues to wish he could find something to trigger a positive change. Each day he exerts all his strength trying to do so but never quite succeeds. He lives each day like that and simply cannot get out of trying.

126. F says that even though, like he always says, that its like living with chronic pain, you have to learn to live with the chronic pain. You know you can't, you try hard to find a solution, a way to end it but you have to basically you have to learn to live with it. He goes back to his back when he had his operation too. It was obvious that the medical people couldn't do anything about the pain so he just had to, all they talk about is pain management. F says what a hell of a way to live, you know, all you have to learn to do is mentally deal with the pain all the time.

127. F says its the same sort of thing here, you just can't, you'd like to change it and, and you can only do so much. But you have to learn to live with it.

128. [!:
How have you seen S₂ change. How, I know he's growing up, that's obvious but other things that are.] F says that S₂ is really good with S₁. He doesn't know if S₂ knows that he's (F) really sensitive to the fact that on occasion he knows S₂ will be rushing off to see his girlfriend or one of his friends or something like that and he'll miss talking to S₁ before he goes out the door and S₂ is really good at that, he doesn't need much prodding but every once .

129. F continues that everyone wants S₂ to do that and F says he wishes S₂ could stop sometimes and just tell S₁ where he's going and who he's going out with because S₁ is very, very in tuned with S₂. S₂ just has to walk in that door and say "hi" and S₁'s eyes are just straining right out of his sockets to turn around and see him, you know.

130. But S₂ is really really good at doing that and he's good with his brother. He hasn't ripped his brother off, he's sensitive to his brother.

126. F compares their situation to chronic pain wherein when a solution to relieve the pain is not forthcoming, then one has to learn to live with the pain. From his own experience with back surgery, F was told that all they could offer him was strategies to learn how to live with the pain, how to mentally deal with the pain. f felt it was a terrible way to live.

127. F equates their situation where, despite their intentions, they can only do so much and so they are having to learn to live with their situation.

128. When F is questioned about how he sees change in S₂ F describes how good S₂ is with his brother, how sensitive he is to S₁. Though F is aware that on occasion S₂ rushes off to see his important other or friends without talking to S₁ but for the most part he needs little prodding.

129. Though they all wish S₂ to continue with his activities, F wishes he would stop and share with his plans and activities with S₁ because he is very much attuned to S₂. Whenever S₂ appears, S₁ strains to see and orient himself to S₂.

130. Yet F feels that S₂ is truly sensitive and kind to his brother and has never slighted him.

131. M says that she thinks she'd like to add in here too that S₂ has shown himself to have a strength of character that she had never dreamed of. M means S₂'s got the stamina in him that was surprising for, you where what S₂, had you turned 19, no you turned, you were 17 and you turned 18 in February. Yeah at that point and uh, she can still remember at the hospital like, just standing his ground, you know when people came around and stuff. Like why aren't you in school! Like I'm here because this is my brother.

132. M continues that having a meeting one day with the social worker and they had invited to come the head nurse and all the disciplines were there. And S₂ couldn't come that day. But M remembers her (social worker) saying to her "oh I never thought M, if you would have wanted to bring S₂". And M says she can remember saying to her "huh, don't you kid yourself, if S₂ had wanted to be here, he would have come whether you invited him or not".

133. M says it was a surprise, you know because S₂ is so quiet and before the accident like he said S₂ was always gone. She means, if they were lucky it was like "hi S₂, hi Mom, I'm going to bed, goodnight dear". And then get up in the morning S₂ would get out of bed and he was off to school. So that was basically the relationship. So all of a sudden they were thrown into this together. It was amazing to her.

131. According to M, S₂ has shown a strength of character for a person his age that she never dreamed of. He was able to hold his ground while at the hospital.

132. Giving the example of a meeting attended by the family and all disciplines, M says that one professional mentioned that they had been remiss and S₂ could have attended. M responded by stating that should S₂ have wished to attend he would have done so even without an invitation.

133. S₂'s behaviour was a surprise in that he is quiet by nature and prior to the accident they saw very little of him. However, with the accident they were all thrown together.

134. [I: *You learned alot about each of you.*] M says oh yeah and many voices together, for sure, it surprised them all. F says he can remember when S₁ was in the hospital and he came in and she (a nurse) was cleaning around S₁'s trach tube. F says that she treated this little cleaning up operation, he guesses it was major surgery. And M had gone off to he didn't know, to mail something, to sign some papers or something like that. S₂ and F were outside the room and the nurse came in and she said "where's his mother?, where's his mother, I wanted her to see me clean his trach tube". F said "well I'll come in" and the nurse said well then okay. So F came in and was watching her do this cause you know he wanted to know how they did it.

135. F says that the next thing, S₂ came walking in the room and he remembers the nurse looking at him, giving him a steel eyed stare like how dare you come in here and S₂ stood his ground and walked right over. And it hit F like a sledge hammer, you know, S₂ just, nobody could tell him he couldn't come in to see his brother have his trach tube cleaned type of thing you know.

136. And F says he thought "what the hell is the matter with me? Why didn't I say, I should have said to that nurse, hey look, we're both going to come in to see this. This is his brother, don't question his rights to be there". But F says he didn't, this was all part of the new experience, they were coming up against alot of things they didn't understand, so they didn't expect.

134. When I comments that they all learned alot about each other all family members agree. F offers an example of the day they were at the hospital and M was off attending to an errand. A nurse arrived to attend to S₁'s trach tube. She asked for M so that she could demonstrate the proper method of attending to it. F explained that M was unavailable and offered to attend himself so that he could learn the appropriate maintenance procedures.

135. S₂'s entrance evoked a glare from the nurse expressing her disapproval but S₂ remained undeterred and walked right over. It struck F forcefully that S₂ held steadfast to his entitlement to observe his brother's care.

136. Awareness of his oversight struck F forcefully. He wondered how he had failed to include S₂ or to communicate to the nurse S₂'s right to also be present. On reflection F believes this oversight was part of their new experience, being immersed in new unfamiliar situations.

137. M starts to say like, like and F continues that he was almost glad to take S₂ up there so that he would get to go in to see him. He says what the heck she was just cleaning up his trach tube for heaven sakes. [I: *But just as you are talking it seems as if there's certain protocols or certain ethical behaviour, like social behaviour, you know, like when you go to a party you talk in certain ways. But this is, when there's somebody sick, there are certain expectations of how the parents, like the mother will behave or the father or the brother or the friends or whatever. But what I'm hearing, is that from all of you, they (hospital) may have their ideas of what it is, but I'm sorry, we have our ideas and you (hospital) are going to do what we say and what we need to do.*] F agrees exactly. [I: *And this is something that, I guess, sounds like it came through for all of you in a split second. It didn't take too long for you to learn that, if I feel that I need to be there or want to be there, then I am going to be there. I don't care what they (hospital) think or say.*]. F says that's right.

138. F says that he had another little experience with the system that prepared them for what they were going to be up against. And when he sits back and some situations differently. M mentions the nurses with a laugh. F says that it was all a learning experience and because they have a certain view of them, they put doctors and nurses in certain categories and they will always do what's right you know, they are really caring people (M attends to S₁'s juice bag and adjusts his shirt) F says that they learned.

139. F says that of course you get knocked around alot, people have their own prejudices which was surprising because if we can if this stuff comes to the forefront of our attention, we see how things should be. He means that these people are there all day long, don't they understand how parents feel. He says they must and how can they ignore that.

137. F found it pleasing to be able to take S₂ with him to observe his brother's care. F recalls it was only a maintenance procedure. I comments that they seemed to be discovering what was appropriate behaviour in such circumstances, what the expectations were for parents, mother, father, brother or friends. However it seemed to I that regardless of what the hospital deemed as acceptable behaviour, this may not have coincided with their ideas and they were determined to do and say what they needed to. As well it seemed that this learning came very quickly

138. F says he has another experience to relate that helped prepare them for what they would be up against. M mentions the nurses with a laugh and F continues that they considered it all part of their learning experience. Originally they had certain fixed ideas about medical professionals that they always do what is right and are really caring individuals. M attends to S₁ and adjusts his clothing.

139. F acknowledges that they endured difficult times since others held their own biases which surprised him. However when in front of them, they were able to see how things should be. F was mystified that often staff showed a lack of understanding for parental feelings despite the fact that they worked there. He is of the opinion that they must understand but he wonders how they come to ignore their understanding.

140. F continues he means he's sure they get to go to lots of conferences on, but they always seem to think they deal with, the only means they have to deal with HOW TO HANDLE parents. [I: *Their training.*] F adds that he remembers one nurse who said this sort of as a joke and they had a big staff meeting and F thinks that M asked what it was about and it was about how to deal with parents. M adds yeah, parents like you (refers to I) and parents like me. F says he means that its obviously they are not taught how to be sensitive to parents and just talk about how to handle and M adds how to tolerate. F says how do you get your way and tolerate these people. But basically he says they get, to protect the system.

141. [I: *When you heard about this, how did that affect you?*] M says that when the nurse said that, well mind you at first she thought it was a joke and she thought those people had the sensitivity of a doombob. She asks I if she know what she means. She thought (sarcastically) they thought that one conference was going to do it. What a joke. M says that they should have been at that meeting. And that's what she said to her (nurse) out loud, "hoh, we should have been at the meeting, we could have told you quite quickly what we thought, how you should deal with the parents. M says that she (nurse) just sort of laughed, but she obviously.

142. F says that the purpose was to be more sensitive to parents. M says no, it was how to tolerate them when they are around, you know what I mean. I'm sure.

143. [I: *How do you see S₂?*] M repeats how she sees S₂. [I: *How he relates.*] M says that well S₂ has definitely changed. Unfortunately for S₂, like he, the year before S₁'s accident, his friends were in the accident and he came so close (shows with fingers) that it could have been him.

140. F assumes that most staff attend conferences which deal with parents yet he is of the mind that the focus is more on how to handle parents. F recalls a staff person who recounted a staff meeting specifically focused on parents to which M adds ordinary parents like us. With input from M, F says it is apparent that professional teaching is not focused on how to be sensitive to parents but rather how to tolerate parents. F maintains that their teaching is for the purpose of protecting the system.

141. * Initially M thought the nurse was joking and she realized the limitedness of the sensitivity of these professionals. Scornfully M indicates that the professional seemed to believe one conference would suffice. Believing that they should have been at that conference, M expressed her opinion that should they have attended they could have helped educate the attendees readily.

142. F shares his perspective that the professionals were to learn how to be more sensitive while M corrects him and states it was more to learn how to tolerate parents

143. * M sees that S₂ has definitely changed. She begins to recount the ongoing tragedies S₂ has witnessed in recent years. Prior to S₁'s accident S₂'s friends were involved in a serious accident and S₂ came very close to being involved himself.

144. M says that she thinks that was the beginning of the change in S₂ because it really shook him up for about three months. M says she's telling this because there's the difference. During those three months (friends were convalescing) she knew this kid was hurt, he was very upset about these two friends because they were really badly hurt. But he didn't talk about it you know. And so they were not comfortable because they knew he was not comfortable so they weren't quite sure what to do with it. But they knew he was hurting

145. M continues that S₁ had his accident and like that was it. (F turns around to S₁ and rubs his left/closest knee and gives it a pat and then turns back to the conversation) The world changed over then. She says that because it happened, well because it happened to S₁, but all of a sudden its geez, this is my mom and dad that's hurting and this is my brother that's hurting and I'm hurting. M says that then the communication started flowing.

146. M says that when X (S₂'s friend) was killed in October, that was the culmination of everything. She thought we, this is where, what's going to happen now because she was quite frankly worried about him (S₂).

147. M says she knew that the kid had a lot of stamina but that's alot to deal with. She means that at 18 years old but he did do what he had to do and he's gone through his depressions and he's gone through alot of rough times and nobody will ever know about it except him and herself and F.

148. M says that because, they sit there and they've cried together, they've laughed, they've talked but they talk and it doesn't matter what he's (S₂'s) got to say, she finds whatever she is doing, she just stops and they sit and talk. and especially at the height of all of this, you know, and so that's how its changed.

144. M believes this incident started the change in S₂. His distress persisted for three months, he talked little about it. While they were well aware of his distress which was legitimate given the severity of his friends injuries they felt it inappropriate to approach him due to his obvious discomfort. They really didn't know what to do.

145. When M mentions that S₁ had his accident F turns to S₁, affectionately rubs his knee and gives him a reassuring pat. Their world changed suddenly for them. The awareness that suddenly all family members were hurting facilitated the opening of communication.

146. The culmination of everything occurred with the fatal accident of S₂'s close friend the following autumn. M was seriously worried about S₂ by this time and wondered what would transpire now.

147. M knew S₂ had alot of strength but she also realized the enormity of what he had to contend with. Aware of his young age and the experiences he has endured, she tells that he has gone through much sorrow and rough times that are known only to himself and his parents.

148. According to M, the primary change is the opening of communication. They have sat together and cried,talked and laughed. However, whenever S₂ wants to talk she will always stop and sit and talk with him especially at the height of his distress.

149. M says that whereas the year before when his two friends were hurt, even though he was hurting too, he couldn't, he obviously didn't feel that comfort zone in coming to them. [I: *Do you think?*] M says that its not cool, maybe, she does not know. [I: *Do you think that if you had not been through all of this that if S₂ would have been really hurting or really having a hard time, you would have been able to sit down? The same thing would have happened, you'd sit down and go through the highs and lows and you would have made the time to sit with him? Or do you think that because after the accident you all.*] F says that he thinks they all just would have.

150. For himself anyways, F says he would never have pressed his boys to sit down and talk about feelings and all that. He thinks he always would have made time for it but he does not think that happened.

151. F says they didn't ever, with him anyway, they were more likely to talk to their mother about their feelings and not to him. But certainly F would never have hesitated to sit down, he means, it felt more uncomfortable. About talking to S₂.

152. [I: *But now.*] F says that now its not. Because S₂ has seen him hurting and crying and that too. So S₂'s seen him in a different light too so he guesses that has changed alot of things. He says there is certainly no hesitation of, and M starts to say that its also.

149. The year before, following his friends' accident, it was obvious that S₂ was severely distressed yet he lacked the assurance to go to them. M wonders if he was still at a stage where it "was not cool" to do so but is not sure. I wonders if they would have still been able to make time to sit and share time with S₂ if they had not experienced all of this to which F believes they would have.

150. For F, he would never have pressed his sons to sit and talk about their feelings though he would have definitely made time if necessary but he does not believe that would have happened.

151. F cannot recall sitting with his sons. as he believes they were more likely to confide feelings with their mother. Yet he would never have hesitated to do so (if asked) even though it felt more uncomfortable.

152. The situation is different now. S₂ has seen his father in a different light, expressing his own emotions overtly. Now there is no hesitation.

153. F says he has got to admit too that he has never had to deal with this, but when this accident happened to his friends on the skidoo and plus Ross being killed, these weren't just cases where S₂ had heard about it. He was present at (adds emphasis with voice) both these accidents when they happened and he was there for all the gore and the screaming and this sort of stuff. He was there and he more than anyone else that was there handled the situation. He was the one there that and M says S₂ went back to the scene whereas his other friend wouldn't. M asks I if she know what she means. To S₂ she asks if this is okay, if its too much for him.

154. F says that he admires S₂ for that and so he means there's very many people, he's 48 years old and he has never been at the scene of a terrible accident and had to try to comfort or do something for people who were, who were really badly smashed up. S₂ has done it and he has had to deal with the, F can only imagine what some of his dreams must be like. You just don't forget things like that. M says no you sure don't.

155. F says they (people) can remember, they never forget scenes they see on television, news about suffering of other people and they sort of haunt you for the rest of your life. But to actually go through it and to still and S₂'s had his problems doing things along the way but he seems to be doing pretty well. And F says he really admires S₂ for that.

156. M says that she does too because you know she often thought if she was in S₂'s age and she was 18 and this happened to her friends or her brother or sister, she doesn't know that she would have handled it as well as he came through with all of this.

153. They had never had to deal with such a situation before. F emphasizes that S₂ had been directly involved in all these tragedies, actually present at his friends' accidents and involved with the call for help and with assisting the victims. M adds that unlike other friends, only S₂ was able to return to the scene of the accidents. With concern she asks S₂ if he is okay given the details shared.

154. F empathizes with S₂ and all he has been witness to. He acknowledges that despite his age, he himself has never been in a situation where he has had to comfort terribly injured persons. F can only speculate as to how this has affected S₂. He believes such experiences are never forgotten.

155. F believes that witnessing tragic events indirectly via the media affects most people profoundly but to actually be present must be even more difficult to bear. Though S₂ has experienced his share of difficulties as a result he seems to be managing and F admires him for that.

156. M also admires S₂ and wonders if at that age she herself would have endured such tragedies as well.

157. M adds that she has to say here too that S₂'s always been a very loyal type, like if he's your friend for life, she means if he's your friend then there isn't anything he wouldn't do for you. But you cross that line and you're finished. Like there's no in between.

158. [I: *That's sort of like all of you though, is it not?*] M says she thinks she should point out here too to I, that as they're all talking here, humph, it all sounds all very saintly, you know that they are this and they are that. But she has got to tell I something, there's some NASTY sides to this story too.

159. M says that there is alot of bad tempers and she knows even with F , she has blown up at him and he's blown up at her and (to) S₂ "get the hell out of here, what are you doing that for, for heaven sake" and he sort of looks at you like "ah gee another PMS day" and walks out the door. There are those episodes too because its not all, its always.

160. M says that the bottom line, the base is always there, the support's always there and the communication is and that.

161. M says that there are low points too when little tempers get hot and there's a couple of bangs on the wall you know, you can see a couple of nicks over there. [I: *Are there alot of those?*] M says less and less as time goes on. There was alot at first, Holy Mackerel.

162. F says there was alot of frustration at first, S₁ was locked up in the living room and they couldn't get him out. He says try living through that situation to which M agrees and F adds it was very, very difficult.

163. M says spilling water. She could spill a drop and go berserk. She picked up a ? and at the chair one day. And she had it in her hand and was going to fling it through the living room window. And she can remember the only thing stopping her was "you idiot, after all the work we did putting those windows in, don't you dare, because you're going to hurt more than yourself.

157. M adds that S₂ is the type of person who is totally committed to his friends and will spare no effort for them. However, given his all or nothing attitude, should a transgression occur, then the friendship would be terminated.

158. M agrees with I that they are all like that but she feels obliged to point out that while this all sounds exemplary, there are also some very nasty aspects to this story.

159. M discloses that they all have easily aroused tempers. Both M and F have stormed at each other as well as at S₂ so that their lived-world is not always harmonious.

160. However, according to M the foundation in terms of their unmitigated support and open communications is always present.

161. At times things deteriorate and tempers flare. There was considerable anger-induced damage in the beginning but it continues to decrease with time.

162. F recalls the frustration that arose as a result of S₁ being confined to their living room in the first months of his return home. F requests we imagine what that might be like. It was very very difficult.

163. For M seemingly minor things such as spilling a little water would trigger incredible outbursts of emotion. Often she would be on the brink of inflicting damage on their environment but would bring herself under control by thinking of the consequent damage.

164. M says she can remember another day, she doesn't know what happened. when she picked up the, you know those canopener things. Well her's is quite big. And she picked it up and she took it and she just flung it into the sink. And she didn't do anything so that wasn't good enough so she picked it up again and "you bastard" BANG and then there was a big, a little dent in the sink and that felt better, thank you very much.

165. [I: *But you have had an affect on something.*] M says yeah, she had to hurt something. It wasn't somebody, she had to hurt something.

166. M says she remembers days where she would go berserk. One day, she had done she didn't know how many loads of wash and she walked into the laundry room. Laughing, M says this sounds kind of funny, it sounds so childish. She hit her elbow for the fifth time on that damn doornob and she can remember lifting up her leg and she says she was ready to put her foot right through the wall. And M swears to I that she could have done it because she had the heft behind it. She was so angry. And then she thought, you fool, you're taking it out on the wrong person. So she called the insurance and lambasted her (laughing) to hell and back. But the consultant came the next day so she supposes it did something.

167. M says those moments were terrible, oh man, she never realized she had such violence in her. Laughing M says it was just awful.

168. F says that they are talking about because they were all going through the same thing and they knew they were all from the beginning. F says that you can't, because you don't feel angry at the time and the other person does, you can't go ahead and jump all over them and he thinks they have learned not to ride each other and M agrees and says she should say that.

164. On another occasion M picked up a kitchen implement and flung it into the sink. However seeing that it remained undamaged she did it again with greater force and vengeance. This time she discerned a small infliction and that made her feel much better.

165. To I's comment of needing to have an effect on something M confides that she felt it imperative that she hurt something, not a person but a thing.

166. M remembers days where she would literally explode. On one occasion, having completed a onerous chore repeated times she happened to hurt a limb on a doornob. In retrospect M finds it humorous and says it now seems childish. But at the time she was ready to vent her anger by damaging a wall with her body and she believes she was fully capable of succeeding. However on reflection she realized she was projecting her anger in the wrong direction. She therefore contacted the appropriate person and vehemently expressed her anger. The following day a solution was initiated.

167. M recalls the frightening nature of those moments and the realization of her potential for violence. She is now able to regard some of those incidents as humorous.

168. According to F all family members were having similar experiences. Somehow they learned to avoid the desire to retaliate when at the receiving end of the other's wrath.

169. F says that (in the past) S₂ might get up in the morning bitching and complaining because he's and M says she would kick his ass and F continues that he would have gone after him more whereas now he tries not to say a word.

170. M says that people that ,and F says that he thinks maybe all their frustration levels are, its easy to trigger frustration.

171. F says he was loading the truck up to go to the dump yesterday and he banged his thumb. M laughs out loud. F continues on something and M had come up and she had brought out a bag of garbage out there just when this happened. And F got so mad he just took the garbage bag and he flung it right to the back of the truck there. And he heard the window crack at the back but it didn't do any damage to it. F says it was such a stupid little thing that triggered it and he gets so angry at it. He wouldn't have cared, he would have probably felt better if he had broken the window. And M never said BOO, she didn't show any sign that this affected her at all. He thinks this is what's helped alot of what they know and not.

172. M laughs and F says let them be angry. [I: *So you, do you think you understand each other uh.*] M says oh she thinks so and F says sure because and M says a hundred time.

173. F says that they know that they all and he feels frustrated sometimes, well M has certainly got to be feeling frustrated sometime and uh S₂ has certainly got to be feeling frustrated, so sometimes you just got to vent it.

174. M says she thinks so too and she thinks with S₂ too, like if none of this had happened to S₂ and you go through your normal course of events. When S₂ lost his temper, cause he's got a hell of a temper, her sweet little angel. Face of an angel but temper's just wicked. Then there, like she has no time for that stuff you see and then F has got a temper too.

169. F gives the example of S₂ beginning his day in an obstreperous mood. In the past F probably would have chastised him but now he refrains from commenting.

170. Both M and F perceive that frustration is more easily triggered in all of them now.

171. F recalls with humour an incident from the previous day when he had hurt himself while loading his truck. M appeared at about the same time with additional cargo. In anger, F strenuously flung the load against the far end of the trunk which resulted in a very loud noise. Though no damage occurred, F acknowledges he would have derived considerable satisfaction if it had. He notes that even minor difficulties have the potential to provoke serious outbursts but the fact that others are able to remain relatively unmoved as M had that morning, has been very helpful.

172. Both M and F laugh and F condones the expression of anger. In response to I's question they both agree that they seem to understand each other.

173. Recalling his own experience F empathizes with M and S₂ and realizes that at times venting one's anger may be unavoidable.

174. M agrees. Endearingly she points out S₂'s easily provoked temper despite his angelic demeanour. She indicates that zero tolerance would have been the norm for such behaviour should this tragic event not have occurred.

175. M says that there's one time when F cracked the jeep, the windshield. She wanted to kill him, she means she did she was so angry. She thought you twit but she realized through all of this, that for men that's obviously more of a release than for women. If she was (?a man) then you would see how violent she became but. F starts to say he thinks and M says she's sorry to F she just wanted to say that under normal circumstances none of these things would happen.

176. M says she wouldn't have tolerated half S₂'s little temper tantrums. But she has realized now that this kid's gone through the same hell that they have gone through. At an awfully young age and it makes her realize that, you realize alot sooner that Jesus he's a human being, he's an adult, he can think for himself and he can hurt and he can cry and he can get mad and there's reason behind it.

177. M says that whereas probably another time and she would have said "eh gee, these teenagers, will they ever learn to live long enough to know anything?"

178. [I: *A little more reasonable.*] F says he found that when M was talking about the crack in the windshield, she probably didn't see things as real, that jeep was his toy. You know and how dare his toy let him down. He says that he was really mad and he broke a windshield but maybe she has got to sort of be a guy to understand that.

179. F continues that like its when you want to start a motorcycle and M says to F that's her point. F says that its just a machine and M repeats that that's her point, the situation yeah, she knows but she didn't say it to trivialize it. She is saying it in the sense that at that time he doesn't have the same sensitivity to somebody else. And laughing she says "you're so stupid you know".

175. M shares her exasperation at F for a former incident wherein he deliberately damaged a vehicle. She realized that frustration tolerance seems to be different for men than women. She also realizes that these incidents would not have occurred given normal circumstances

176. M would not have tolerated S₂'s temper tantrums in the past but she realizes he has had the same tragic experience. Despite his young age she recognizes he too is a human being capable to a myriad of emotions.

177. On another occasion M would have been more likely to generalize S₂'s behaviour with that of other immature adolescents.

178. When questioned about being reasonable F reflects that M was probably unable to envision the fact that he considered his vehicle as a toy and was insensed that his personal toy had let him down. F is of the opinion that M would have to be a male to understand such thinking.

179. Both F and M make clear their viewpoints which seem to coincide; F that his vehicle is just a machine and M that F lacked sensitivity to other persons to which she adds that he lacks awareness.

180. [I: *You're more open.*] M says that's right, they're more quick to understand why the temper is behind the actions sort of thing or the actions are behind the temper. [I: *Why the person, like the person is entitled to be who they are.*] F agrees and M says that's right and adds that as long as she doesn't wreck her keyboard.

181. F says to S₂ that this is not an open invitation to put a hole in the wall or something. He says go and read a bunch of magazines.

182. M says that's right to S₂, that 's why they bought, actually they bought him a punching bag last Christmas. S₂ says he was just thinking of that. [I: *A punching bag?*] M adds that it was just for that purpose because S₂ had a lot of anger. [I: *Does it help S₂?*] He says yes, actually it feels good. Laughing M adds that she wishes to hell she had it before she wrecked her bathroom door.

183. [I: *What's it like for you to see your parents like this?*] Laughing quietly S₂ says well sometimes he feels like he said walking out because it will be "uh Mom" and then "OH WHAT?" M laughs. [I: *That doesn't really upset you or make you go on the defensive?*] S₂ says no, he just says 'NOTHING'. M continues to laugh and S₂ adds that M will come out, she'll be happy and he guesses like she really didn't mean to do that.

180. M agrees with I that they are more open and also more readily able to understand the rationale behind the behaviour. F agrees with I that each of them is entitled to be who they are to which M jests as long as she does not ruin her keyboard (a favourite possession).

181. F recognizes that this is not licence to damage their personal environment and that they ought to find a diversion.

182. As M mentions the punching toy they purchased expressly for S₂ to help him with his anger, S₂ adds he was also thinking of this. He confides that it feels good while M asserts she wished she had had access to it prior to some of the damage she has caused.

183. When asked how he perceives his parents' and their anger S₂ confides he sometimes feels like extricating himself when he is the recipient of curt responses. All family members seem to regard such outbursts as acceptable. In turn S₂ will bark a response often to subsequently find M in a normal frame of mind so that he senses she did not really mean to be abrupt.

184. S₂ says he doesn't really say much but he is quick to have a temper especially like in the mornings and stuff like that. He means it always pisses him off that when he is pissed off and someone tells him to calm down to which M laughs out loud. [I: *That's what we're saying, that you're not entitled to be who you are. At least they.*] Everyone talks at the same time. F and M say they are guilty of that and F adds that he guesses they are more sensitive now. He guesses its easy to say, well you see the other person is upset about something. Its easy to find the reason why, whereas before you'd say 'well what the heck are you so upset about?' [I: *You're just not supposed to.*] F says yeah that's right. Well now they say well this is probably got something to do with the situation.

185. M says that she might add too, S₂ her darling, to which S₂ laughs and M continues that S₂ is also in a bad mood Miss I because he perhaps got up too late which he does every morning, you see and its his own dam fault. So she says that really after 19 years of this she sort of gets mad to which S₂ laughs and M says she just wanted to say that to defend herself and laughing she says so you see I its not all.

186. [I: *Well, what I see is that you work it through, like there's the obstacles, but like you don't hit the brick wall and get stuck there and stuck there and keep trying to bash the wall. You sort of back up and reassess the situation. And this is I think what you were saying its not all the same and I'm wondering how, how you got to the point where you are able to back up and re-evaluate. Was that a normal thing, like a natural progression?*]

187. F says he thinks its a survival thing because if they don't do that they are just not going to make it. M agrees and F says if you have it. [I: *Some families do not make it.*] M agrees. [I: *And you are making it. I'm not saying that its rosy or whatever but you are making IT. You are making a life for yourselves.*]

184. S₂ tries not to say much especially since he is easily provoked in the early morning. He finds it extremely disconcerting to to have someone tell him to calm down when he has been provoked. Both parents accept responsibility for that. F shares that in the past they would have been more inclined to wonder at the origin of the outburst but now they seem more able to acknowledge the underlying situational nature of the outburst.

185. Wishing to relieve herself of any misunderstanding, M shares with I in jest, that the reason S₂ is often obstreperous in the early morning is that he habitually rises late and over time she loses her patience. All laugh. M points out that all is not harmonious.

186. I observes that as a family they seem able to back up and reassess their situation rather than hitting the wall and remaining stuck. She wonders how they have come to that place and if it was a normal evolutionary process.

187. From F's perspective it is related to survival so that they may transcend this situation. Acknowledging their struggle, I reflects that as a family they are making a life for themselves unlike some families who remain stuck.

188. F agrees and M says that she thinks they have to have, they have to have that strength of character. She doesn't know how else to say it, she know certainly.

189. F says that he sees that S₁ is the focus and above all else they have to do what they can to help S₁. And to him, he just sees it as, they have got to keep a lid on things because otherwise he's the one that is going to suffer and its really as simple as all that.

190. [I: *How would?*] F says that if they can't hold they can't keep the family together, what's going to become of S₁. Its as simple as all that to him.

191. M adds that beside too, their kids are for F and her, their vows were very important. She can remember they were married really young, like she was only 18 and she can remember people saying "tsk, these marriages never work".

192. M continues that marriage vows to her were not just something you said overnight and then the next day well I don't like the way you handle the facecloth, I'm leaving you know and you go away. So they worked hard to come to this point.

193. M says their life has not been easy, those first few years they were married, there were times she hated F as much as she loved him. She asks I if she knows what she means, probably more so. M says that F has a certain way, he was different and she was different and uh, so they've worked their way through these things and got to the point where they are and stuff.

194. M says that it was the same for their kids. Lets face it when you are raising kids its not always, its not all cutesy wutesy and sweet little smiles and all that stuff. There are hard times too.

195. [I: *You are all strong willed.*] M says that they are all pretty bull-headed, oh yes.

188. Both parents agree and M attributes their success to strength of character.

189. From F's perspective, their plight is simple, S₁ is their centre of attention and unless they control their difficulties, he will be the one to suffer.

190. For F, maintaining the cohesiveness of the family is the key to being able to adequately provide for S₁.

191. M shares that their children are symbolic of their marriage vows. she remembers the misgivings which were expressed by others concerning their youthful marriage.

192. For M marriage vows were not taken in passing only to be discarded for trivial reasons. According to M they have worked hard to get to this point.

193. M acknowledges that their life has not been easy. In the early years she both hated and loved F, at times more the former than the latter. Given their differing natures, they had to work through their differences in order to get to this point.

194. Raising their children has been similar in that there are difficult times along with the fun and joy.

195. When I comments that they are all strong willed M corrects that to bull-headed.

196. F says that worse than anybody and he thinks they have grown through the years too. He can remember back when they first got married laying the law down to M that, you know, if she had something to say, he was willing to listen but when it came down to the final decision he was the man of the house. F says its funny and to be absolutely unabashed and unshy about saying that. M agrees and F continues that what could he, if they couldn't come to an agreement, he won.

197. Lots of talking by everyone. [I: S₂, *did you know this?*] S₂ laughing says no. [I: *That your dad was like that?*] Again laughing S₂ says no he didn't.

198. M says that no this was way before S₂'s time fortunately. F says he never thought, like he said about chauvinism, oh yeah for sure.

199. M says its different and F says its got nothing to do with S₁'s accident. He would be totally uncomfortable telling M how to think and how to look after money. He means he doesn't want to run. It won't make him feel better telling her how to think and what to do, he means he just anymore than he would want her to tell him what he should do

200. Laughing M says that she thinks they sort of found that out fairly early in their marriage and F also laughing says that the fact that M stands her ground helps too.

196. F perceives himself as maybe more difficult He remembers early in their marriage laying down the laws of the home. In retrospect he sees it as humorous but during the early years he unequivocally and unabashedly decreed that while he was willing to listen to M's perspective, should a stalemate arise, then his word would carry the decision.

197. All participants laugh. S₂ indicates that he had no knowledge of his father's attitude

198. M indicates this was before S₂'s time and F remarks that though he never considered the notion of chauvinism but in retrospect he definitely qualified.

199. M says its different now and F admits S₁'s accident has in no way influenced this change. Now he would be totally uncomfortable trying to dictate how M runs her life just as he himself would resent her doing the same.

200. Laughing together M believes they found that out early in their marriage and F admits that the fact that M stands her ground also helps.

201. M says that she can remember she told him she had to buy a new bra and F says that M was upset and he didn't believe this nor remember it. M says oh yes you were and F repeats that he doesn't believe it ever happened. M says he was, and he did. She said she had to buy a new bra and he said "oh how much is that going to cost (she mimics a man's voice). F laughs. M says she hung up the phone and she called F's mother and she said "Mother (F chuckles along) I'm telling F I have to buy a new bra and he asked me how much it's going to cost" F's mother said "Tell me M, who signs the back of your paycheck when you get it?" M said "well I do" F's mother said "well you get the hell out there and you buy what ever the hell you need and don't you ever let any man tell you what you need". (F chuckles) M says that that damn bra which was twelve bucks cost F 98 because she bought a new pair of pants, she bought 2 bras and a sweater (she slaps the table for emphasis).

202. M says that from that night on, life in their household was never the same. She laughs loudly. M continues that they have grown to laugh about this but at the time that was very serious and I has to understand that.

203. S₁ snorts loudly. [I: *But that, the way we are socialized, like that men should think this way and women should think this way. Or dads should think this way and moms should think this way.*] Both F and M say yes. [I: *Or uh, parents of uh, injured loved ones should think this way uh, and the hospitals expect.*]

204. F says that they don't fit the mold. [I: *You don't fit the mold and then you also changed the mold to fit you. Like you stand, you're able to figure out what is most important here.*]

201. M begins to recount an incident from very early in their marriage which F states he does not remember nor does he believe. According to M when she indicated to F that she needed to purchase a piece of personal apparel he questioned the cost. Feeling intimidated, she called F's mother and recounted the story to which her mother-in-law responded by asking M who signed the back of her paycheck. When M replied she did, her mother-in-law exhorted her to make her own decisions and never rely on the decisions of others. In the end one small purchase cost F considerably more in that M purchased a complete outfit. Throughout the recounting of this incident all family members seem to enjoy the mirth of the content.

202. According to M, from that night on, the tenor of their household changed dramatically. Though they have grown tremendously from this experience, at the time it was very serious.

203. S₁ snorts loudly. I reflects that they seem to be talking about socially expected behaviour.

204. Agreeing with F that they do not fit the mold I adds that they have also changed the mold to fit them so that they are able to figure out what is most important to them.

205. M agrees and says she can remember they were having that meeting about taking S₁ home and laughing she tells of the other side of the home care, the Ottawa side of the home care. She says that it was like "well we know you're going to have to, you really need and dadadad. And M remembers at one point, she doesn't know what point she had said, it was something to the effect that "this kid is going home, in an ambulance or in my truck but we're going home, so like in case you have any doubts about where we're going", because M guessed they wanted to make dam sure they were.

206. F says they were talking about how months from then they would have it all arranged. F said no, two weeks from now he's coming home and he meant that. F says that if he had to get S₂ and himself and pick S₁ up physically and put him in the back of the pickup truck. S₁ was going and M adds that believe me, F would have done it.

207. I says oh yeah and F says they pressed a button because that was it at the hospital and "He's coming home, we'll take care of it".

208. M says that then the meeting went on and on and on and finally something else was said and she stepped in too and she said "look, I don't give a damn what you have to do, we're taking him home regardless so I don't really care what your little problems are, you work out your problems, don't involve us in it, you just tell us when the equipment is going to be delivered".

209. M says to F that she can still remember the social worker, she had just been switched to their floor and she had only known them for 10 minutes, throughout the meeting. She was sitting there and M could feel her back going up and M says you know the thumbs up sign (behind her back) and good for you.

205. With reference to the meeting arranged to discuss S₁'s discharge home M recalls the city based branch of the home-car services repeatedly pointing out the accommodations which were required. Finally in exasperation M asserted in no uncertain terms that S₁ would be going home even if she had to orchestrate it herself. M believes home care services wished to assure that the family was prepared.

206. F adds that when the professionals indicated an inordinately long time frame so as to accommodate needed arrangements, F asserted that they had decided to take S₁ home at a time of their deciding even if F and S₂ had to bodily remove S₁ from the hospital and transport him themselves.

207. Something happened, the decision was made and they became resolute in their determination to care for S₁.

208. The meeting dragged on to the point where M stepped in and announced that S₁ would be going home regardless of their difficulties. She told them to solve their own problems and simply advise them of delivery dates for the equipment.

209. M recalls a new professional assigned to their floor who knew them only a very short time who, upon hearing this altercation, discreetly indicated her approval.

210. F says their own home care there in the [rural area] area is just fantastic too. They were right behind them from the word go. M says dam right and F says they never waited a day for anything. [I: *You mean that now you can count on them.*] M says yes 150%. F says they are very supportive and M says their director is very supportive of them .

211. [I: *Where, how do you see the next phase for you?*] F asks if she means for their life. [I: *Yeah, for S₁, for you because you can't, we're not going to separate, as you said, if you go some place its only if you can go some place that you can take S₁ with you.*] F agrees. [I: *But in terms of the phase, like you know, you have gotten alot of information, you've got a system of how you care for him that you feel comfortable with, that you are doing their best. You're always on the lookout for more and whatever, so how do you see the future unfolding?*]

212. F says that basically, like that, he's not looking for any miracle, he thinks there is no reason not to expect slow progress on S₁'s part. They will keep their eyes and ears, maybe more vigilant now to be aware that there's possible things for them to do that they are not aware of, its just a matter of fact of keep, be vigilant, keep their ears and eyes open for things. They're basically going to be on their own, and just a continuation of that.

213. [I: *How about you M?*] M says she guesses, its funny when she looks into the future and she thinks even of S₂ getting married and having his kids and him getting on with HIS life. M says she visualizes S₂ living there and laughing she says I shouldn't laugh because S₂ used to always say this "so Mom where are you going to live when I get married?" M asks I if she knows what she means, like where are you and dad going to live when I get married, I mean he really means that for sure. But M finds it hard to think about the long term.

210. Both parents relate the merits of their local rural-based home care services. They provide exemplary care and services as well as being totally reliable. Furthermore the director is fully supportive.

211. I asks how the family sees the next phase of their lives evolving. She further clarifies her question and emphasizes the inclusion of S₁ as an inseparable member of their life-world and notes that they already have in place a system of care which they are comfortable with, that allows them to do their best and they are always on the look out for more appropriate services.

212. F acknowledges the impossibility of miracles but is firmly convinced that S₁ will continue to make slow progress. At the same time they will unflinchingly persevere in their search for new things to do and provide for S₁. However they are resigned to being on their own.

213. For M the prospect of the future is different. In contemplating S₂ getting married and having his own family she always visualizes him in their home. She shares a long time family joke wherein S₂ seriously asks his parents where they will live once he marries, implying his desire to reside in the family home. As for the distant future, M finds it difficult to consider.

214. M says that eventually she guesses because she hopes its because she does the actual care-giving everyday, so she lives for the moment, from day to day. M says that she never sees it changing. She only ever sees it this way and she doesn't know, she can't, she is like F, like you know people say "oh you know, he (S₁) could could just do this and he could". M says that maybe he will and maybe he won't but she doesn't dwell on it, so she is basically left. Whatever she gets to the moment she'll deal with it. [I: *its a gift.*] M says that yes, that's right, its worth it, that's right.

215. M says she really has a lot of trouble dealing with what happens in the future, she thinks too because she is deathly afraid of something happening to her. If she thinks of the future, in the future she is older. She asks I if she knows what she means.

216. M says that its, she is slowly coming around though. Very slowly because she still hasn't dealt with this, that you know you can't worry about the things you can't control. But she does worry about them because she knows there is not control.

217. M says that she can't control S₂'s life and she can't control F's life and, and S₁'s life she only has so much control over it. But she can't control what is going to happen to her, she hasn't worked out a way yet, like she hasn't been able to get to that point.

218. [I: *Maybe that will be the next thing for you? I mean who knows how long a stage is going to be.*] F says yes it could be. It certainly isn't so far, so far they basically live from day to day.

219. [I: *How about you. How do you see. I know you are finishing Algonquin and you're in the program you like How do you see things for yourself and your family?*] S₂ says he doesn't know, he has never really you know looked into the future, he can't actually.

214. For the present, M lives each day as one and sees little change. This is her only reality and she is unable to see it otherwise. She believes she is like F in that she takes the positive predictions of others only in passing and dwells little on what might be. Consequently she is left with her everyday reality. M agrees with I that whatever she gets is a gift and its worth it.

215. The difficulty M experiences with contemplating the future is directly related to her profound fear of her own demise. In visioning the future she inescapably sees herself as older and she asks if I understands.

216. M feels that slowly she is coming around. She struggles with the need to deal with the fact that it is inadvisable to worry about that which is impossible to control and admits that she continues to worry precisely because she knows there is no control.

217. M realizes that she has no control over F and S₂'s lives and only limited control over S₁'s life. More importantly she fears the fact that she has no control over her own life and realizes that she has not even come close to addressing this issue.

218. I tries to reassure M and states that this may be part of the next stage for her and that this stage may take awhile. F agrees and says that so far they have not moved to this issue as they live mainly from day to day.

219. I asks S₂ how he sees the future for himself and his family given that he is completing a program of his choice. S₂ says he does not know, having never contemplated the future.

220. [I: *Okay, maybe I'm getting a little too broad. I'm wondering, you know your parents have been so focused on getting the right things for, that S₁ needs right now. And to do for you also, you've a car, you've got a place to come here and you get to school and things like that. So that's been focused on, getting the right things. Now how do you think that's going to continue, being focused on that or do you think its going to move into other things.?*] S₂ says that he thinks it won't change all that much really except for once he gets older and he won't depend on M and F as much.

221. [I: *Do you see yourself uh, leaving home after you finish your course next year?*] S₂ says no he is going to start the second part, its all sort of different programs.

222. F says he's certainly not like he, like before he guesses he means he could deal pretty well with his kids getting older and maybe moving out of the house and maybe a new phase of their life would be starting. Now for himself, he doesn't look forward at all to the day when S₂ may want to leave the nest here and he's much more, he'd really like it if he would stay there for the rest of his life.

223. [I: *It makes you feel more secure?*] F says yes it does, yes things have changed right now and he really likes that, to have the kids around more. F means that he doesn't know if he would handle that so well anymore.

224. [I: *It might be something that will have to be dealt with when the time comes.*] F says yes for sure. [I: *Its not tomorrow, that would be an issue that will have to be faced with.*] F agrees.

220. I clarifies her question by adding that presently the parental focus is on providing both S₁ and S₂ with that which they need, for S₂ it is in terms of his education and transportation needs. She wonders if he foresees things continuing in the same vein to which he replies that he believes it will continue similarly until he becomes more independent.

222. When asked if he considers leaving home upon completion of his program S₂ replies that he intends to go on to the second part of his program.

223. F joins in to say that previously he was more able to deal with the idea of his children's growing independence and possible departure from home and their own beginning of a new phase of life. However, now he does not relish the day S₂ may wish to depart their home. In fact he would sincerely prefer S₂ to stay with them for the rest of his life.

223. * F agrees that such an idea help him feel more secure. He confides that things have changed for him and he sincerely enjoys having his children around. On reflection he does not know if he would be able to manage their departure in a positive way

224. I tries to reassure F by saying that this issue does not appear to be imminent but will require attention at some point in time.

225. M says she knows because when S₁ left she never found it easy. She knows when S₁ left he was just going to Ottawa and was home every weekend. Laughing she says she found that hard, holy shoot, that first night S₁ walked away, it was terrible. M says that she knew for S₂ it was going to be the worst cause he is her youngest and once he is gone the geez, they are really gone.

226. F says that whereas for him, its like when S₁ was in town. They can, he can do things for himself, that's right, and those, of course he thinks its easier for a father to see his sons evolve the way they are supposed to.

227. F says that he feels like he's more sensitive to that right now. [I: *Well you're sort of ambivalent, like you're not really sure.*] F says yes, that's right. He adds that they (sons) progress really slow too but then he thinks he has a hard time now, you know seeing but that's far off in the future because S₂'s got his education. F says he told S₂ "you know S₂, you don't have to feel in any rush. I don't care if you go to school for the next 10 years. You can stay here. There's absolutely no problem at all. We want to see you here, you know and actually be happier".

228. [I: *It would help you.*] F says that's right. [I: *Give you time to sort things out.*] F says that given the situation, everything, despite the fact that S₂ is here and the family 's past is really an issue for him. So F sees that things have changed that way and maybe its not as easy to see the end, that things evolve.

229. M looks at S₂ and asks him if he looks forward to moving out and he says no. She asks if he ever thinks about it and he says well he has thought about it, he's not really. M continues that they are sitting there say, she just was thinking they were saying these things to him and figuring what was he going to do when he leaves and he is not going to and she doesn't want him to feel guilty. [I: *Maybe he does want to leave?*] M says oh maybe he does but that 's okay too.

225. M joins in and recalls S₁'s departure to attend higher education. though he was relatively close by and able to visit on weekends she acutely remembers the first night he left. It was terrible and she knew that the departure of S₂, her youngest would be far worse in that it would specify the finality of their situation.

226. F believes it was easier for him, being a father to watch his sons mature. He understood that S₁ was able to do things for himself while away from home.

227. F feels he is more sensitive to these issues right now. When I suggests that he is somewhat ambivalent he admits that while he sees their maturation as slow he also has a hard time contemplating this. He therefore considers it to be far in the future especially since S₂ still has his education. He reassures S₂ that he is most welcome to remain at home regardless of how long his education takes. In fact he confides that they might even be happier if he would remain.

228. * F agrees with I that this would indeed help him, give him the needed time to sort things out. F admits that his situation has changed and it is difficult for him to contemplate the end, that things do evolve.

229. M asks S₂ if he looks forward to leaving home to which he replies no but that he has considered it. M endeavours to reassure him that despite this conversation she does not want him to feel guilty. When I suggests that maybe he does wish to leave M adds that that too is permissible.

230. [I: *Before we, are there, is there anything that we've not talked about that you feel it would be important to mention. In terms of how this has affected your family?*] Silence for a minute or so. M says no she thinks we have covered just about everything.

231. M adds that the feeling of isolation was one of the big things, like they are really isolated from their family and their friends. It amazes her how standoffish.

232. [I: *If you were in Ottawa would, do you think it might be different? People coming?*] M says no, she thinks she is glad they are not in Ottawa just because of it, because they wouldn't want to be bothered.

233. F says that he is very sensitive too, he finds that sometimes he asks M "how's your day" and she will "well I was talking to this one and I was talking to that one and this person dropped around" and he finds he is very sensitive to, the first thing that comes to his mind is "well yeah but who's looking, who was talking to S₁ or reading to S₁ or who was with S₁ while you were talking to this person. F says that he finds but he has never said anything to M about that before. But what he is worried is what if one of her friends calls up or her mother or his mother. The first things that's on his mind is "oh yeah, well just what was S₁ doing when this was going on, you could have been reading to him or talking to him or doing something. [I: *What is your most important priority M, right?*]

234. F agrees and adds that then he, he understands but then he has never said anything. This is the first time he has ever even mentioned it to M. This is the first thing that comes into his mind. But he understands too that she can't be isolated from everybody, he understands too that.

230. I asks if there is anything as yet unmentioned that they believe to be important. M believes we have covered most everything.

231. M then adds that the feeling of isolation is the most problematic for her, her sense of isolation from family and friends.

232. Contrary to the expectation that living in the city, closer to others might make it different, M suggests that living where they do is preferred in that they are more able to control who visits.

233. F finds increased sensitivity to how S₁ is cared for while he is away at work. In particular he becomes greatly concerned about S₁ as soon as he finds out that M has been attending to telephone calls. He worries that S₁ is unattended and is being neglected. F has never shared this concern with M until this time. He agrees with I when she reflects that he wonders if M knows what their most important priority is.

234. F admits he does understand the situation and the fact that M has needs of interpersonal interaction of her own but nevertheless it is still the first thing that enters his mind. He repeats that he has never mentioned this to M before.

235. M says that she has to and F continues that M has got to, she has got to deal with these people and he knows she doesn't gab though and S₁ is languishing away somewhere. It surprises him how sensitive he can be, the first thing that comes to his mind, he thinks a lot of the sensitivity is too, is because he is not here.

236. [I: *To take over.*] F says to take over and so he always wants to know every second of the day that S₁ is wide awake, what's been done for S₁ and that can't occupy every second of the day. M says that of course not, S₁ needs rest periods and time for himself to which F says he always liked a person who does what he wants. He is swift enough to cool it too and asks if I knows what he means. "Well this is silly, you mean you know M won't be on the phone for half an hour talking to this person.

237. [I: *What's it like to hear that from F?*] M, laughing a little says that it doesn't surprise her because whether he knows it or not, she knew that is how he felt. She says she knows him so well now, she means jeeppers, after 26 or 25 years whatever and they both chuckle. But yes, she knew that and to F she says oh geez, she could read that by the tone of his voice, for heaven sakes.

238. M says that the thing is, she could sit there and say "it kind of annoys me" but it really doesn't because she tends to ignore that kind of stuff because she knows that down deep, if the phone rings right now, F could be sitting right beside that phone and like, she would have to get up and answer it because he would ignore it. F chuckles and M continues that it has to be answered because it might be important.

235. M explains that it is often necessary that she attend to these people and she reassures him that she does not chat while S₁ languishes unattended. The intensity of his sensitivity has been a surprise to F. He believes his own absence contributes to his heightened concern.

236. Given his absence F always wants to know what is being done for S₁ while he is awake. M points out that S₁ requires time for himself and time to rest. F prides himself with trying to control himself and his attempts to reassure himself by thinking that M will make her conversations as short as possible.

237. When asked by I how she felt hearing those concerns from F, M lightly shares that she was not surprised as she knew how he felt even if he did not. Having been together for so long she believes she knows him well. To F she says she could tell by the tone of his own voice.

238. M confides that she herself could share her annoyance at this revelation but in reality it does not affect her in that she is able to ignore such things. In addition she knows that F himself tends to be oblivious to the telephone's ring and she is therefore relegated to insure the phone is answered just in case it might be important.

239. M says that for the most part she could care less if these people called and laughing adds that she means that she has to be nice, she has to do what she has to do. F says he can't help it, the people who would call up and want to talk to M and M says that that's because she doesn't spend every minute of the day doing things with S₁, you can't do that. Because she says that unfortunately she gets 4 or 5 hours of sleep at night and so sometimes she needs just to reconnoitre with herself, just 5 minutes she will sit and she will have her lunch and she will watch something on TV or whatever. And because she needs that time to. [I: *To recharge your batteries.*] M says that's right.

240. M says that beside that S₁ needs to be, you can't go at him constantly all day, you just can't, he just couldn't handle it, you can only do that.

241. F says he guesses its partly because he, he wishes to heck that he, like he really enjoys it, like yesterday going to cut the grass. S₁ came out on the deck and everything. F says he'll cut grass for 10 minutes, shut the lawnmower off and come up there and talked to S₁ a little bit. He means chat with him. And F guesses it sort of suits the way he putters around the house on the weekends because he can't, he doesn't have the energy anymore (S₁ snorts very loudly) on all things that could be done. He has to pace himself more and this is, it really doesn't have that much to do with S₁'s accident, he was already starting to slow up before it happened. He is just more content just to put things on a priority list, putter away on them. He says he can't.

242. [I: *But you combine several things at one time.*] F agrees and says it sort of suits him just fine here, he just works for a little bit and goes and talks to S₁ for a bit and then works a bit more.

239. M cares little about most of the telephone calls but feels she must be nice and do what is required. F is unable to help his concern but M adds that she does not spend every minute of the day with S₁. Since she gets very little sleep at night she requires some time during the day to herself, time for lunch, for a little TV. I reflects that she needs to recharge her batteries.

240. M points out that S₁ needs time to himself, he is unable to endure constant activity all day.

241. On reflection F admits that he wishes, that he enjoys his own time with S₁. Just the day before he had S₁ outside with him while he attended to yard chores. He finds it suits his own needs to be able to alternate work and conversing with S₁. He is now more content to slowly work his way through chores. Interacting with S₁ helps him pace himself and has little to do with the accident.

242. I reflects that this allows F to integrate several activities at one time to which F illustrates how he alternates between chores and being with S₁.

243. [I: S₂, how about for you? Is there anything that you feel is important to mention that we haven't talked about or your parents have not talked about or you haven't had a chance to talk about.] S₂ says well and M says "here's a chance for you to be right candid S₂".

244. S₂ laughs quietly and says well he was just thinking about, we were talking about how people had changed and stuff like that. He just finds for himself that uh he feels more sensitive, alot more like emotional and stuff.

245. S₂ continues that he know his mom was saying he had stamina and stuff like that. He just, its with, like his friends and he used to go drinking and stuff like that. But finally well, he sort of like is amazing himself, never really, or maybe he did subconsciously but never really stopped to really cope with anything.

246. S₂ says he noticed when this first accident, when his friends were in the accident, the first thing he did when he got back to the person's house was somebody go and get me a beer and a drink and after that it was like maybe if it works that's all he thinks about.

247. S₂ says he now finds when he drinks he gets, if he goes past the point he gets extremely violent, like basically schizophrenic, like one minute he could be ready to kill someone and later on he could be crying or something or telling people he wished he was dead or something like that and he thinks its just he's worried, he wants to get off the drinking on his own. Safety, he just does not know.

248. F says its a bit of a worry for M and himself because they worry about how much drinking S₂ is doing. F says S₂ doesn't seem to have a great tolerance for, especially alcohol. He says they are not drinkers themselves and he wishes S₂ didn't have that need sometimes.

242. When asked by I if he has anything more to add, M jests and encourages S₂ to use this opportunity to be candid.

243. Laughing quietly at his mother's remark S₂ discloses that on thinking of change, he feels more sensitive and alot more emotional now.

244. Reflecting on his mother's comments that he has stamina S₂ finds his own behaviour amazing to him in that he never stopped to cope with any of the things that have occurred to him. He wonders if he may have subconsciously.

245. On reflection S₂ recalls that following the first accident, his initial reaction was to request an intoxicating beverage and finding it effective to believe it will help again.

247. S₂ observes that beyond a certain level he is likely to become extremely violent, in his words schizophrenic, in that he experiences extremes shifts in emotions. He is gravely concerned and wishes he were able to avoid the need for intoxicating agents.

248. Both parents worry about S₂'s intoxicated behaviour. They recognize his lowered tolerance for alcohol and since they themselves do not partake, they wish he was able to abstain.

249. F says he trusts S₂ that he'll not be able to drink and drive. He always said to his boys "I don't mind if you do risky things as long as you are well prepared for it. But please, please don't ever do anything stupid where we've got to apologize for what you did afterwards.

250. F says that really, really worries them but he worries too that S₂'s drinking, does he have the presence enough of mind, enough to say well I can't drive. [I: *What do you think.*] F says see he does not know what to think because though he hasn't seen S₂ do it, well if somebody gets to the point of drinking they're not going to necessarily make rational decisions and you don't make rational decisions if you're under the influence of alcohol. F says its a real, this drinking is a real problem for them. [I: *A worry.*] F continues a worry for them and he worries about S₂ because he'd just as soon.

251. M says that last night S₂ was at Stevie's and he didn't come home because he had been drinking and that was just down the road there. M thinks that having the new car makes a little difference too and jokingly the threat of being shot she thinks is a second big incentive there to do something about it.

252. [I: *But that maybe in the next phase for S₂, how to cope. Because you said that all this came up so fast for somebody so young who ?? doesn't inside.*] M agrees. [I: *And how do you manage? I mean, we know what, how difficult it has been for you, for both of you and all of you together. But, how he's going to work through this and then, maybe what help does he need, outside help or what help do you all need to help S₂ work through. Because obviously all that stuff is there and it needs to be attended to.*] M agrees and says for sure.

253. F says that they have seen it themselves, its just below the surface with them. Sometimes it doesn't take that much to bring up all those feelings and certainly he got them the other day to which M says that's right.

249. F trusts that S₂ will not drive while inebriated. He has always taught his sons that it is permissible to engage in risky activities provided one is well prepared but it is unacceptable to do something foolish for which an apology will be required later.

250. As well they worry that S₂ will not have the presence of mind to make appropriate decisions while inebriated. When questioned as to his intuition, F confides he does not know. While he has never been witness to S₂ driving while inebriated he does know that often rational decisions are difficult to come by when inebriated. F repeats that S₂'s behaviour is a grave concern to them.

251. M notes that just recently S₂ had opted to remain at the home of a near-by friend while inebriated. M speculates that the acquisition of a new automobile is a significant incentive and in jest she offers the fear of serious parental retaliation as a secondary incentive.

252. I reflects that how S₂ copes with his problems may occur in the next phase and pointing out the extenuating parameters of his situation (age, suddenness of tragic events, difficulties for all of them) she wonders how S₂ will work through and what kind of assistance he might find helpful given that there are many issues which require attention. M agrees.

253. F is aware that such issues and concerns lurk beneath the surface for all of them and it takes little to provoke their reappearance as he himself experienced recently.

254. S₂ says that its as M and F tell about, and F saying he's had like dreams of violence and stuff.

255. S₂ says that he has noticed, nothing seems to affect his sleep, he doesn't really dream about anything when he drinks.

256. S₂ says he couldn't see himself, because if he got mad enough he might kill someone. He says he remembers one time where, it was after S₁'s accident and he and a couple of friends went to this Chinese restaurant in a [neighbouring town] and he was drunk anyway. He was sitting there with all his friends and this guy, he said something and S₂ heard him or whatever and so he started to mouth him. He remembers it started getting sort of intense and he remembers he, like scaring himself when he was sitting there. He grabbed the (phone rings very loudly) knife off the table and just sort of put it in his pocket and he, he just felt himself getting scared and it always seemed to go. F says that for sure, they have talked of this and they know this is a worry for them too.

257. [I: *What held you back, though, you said you took the knife and you put it in your pocket and.*] S₂ says that nothing ever happened. He laughs nervously, so there's nothing.

254. S₂ refers to observations made by his parents and the violent dreams experienced by F.

255. S₂ has experienced to the contrary, no sleeping difficulties and an absence of dreaming especially while inebriated.

256. However S₂ mentions that he believes (fears) if his anger escalates he might inflict fatal harm on someone. He cites an example in a local eating establishment where he provoked another person while inebriated. The situation deteriorated to the point where S₂ seized a table implement and hid it in his pocket in preparation to do harm (Telephone ringing disrupts conversation). S₂ recalls the fear he experienced. F confides that they are aware of this incident and deeply concerned by it.

257. When asked how this incident concluded S₂ nervously shares that nothing further transpired, nothing happened.

258. S₂ says he remembers one time also last summer he guesses it was and he had been drinking and he was using the hard stuff and that was like any time he drinks. And someone was saying, he got in this argument in a poolhall in the [nearby town] and he doesn't know what he did, he got mad. Some guy was pissing the owner off and when S₂ walked in they told him to get out. So when he walked out he sort of slammed the door and it went flying around banging and he (person in the poolhall) started yelling at S₂ and S₂ started yelling at him and then later on that night, one of S₂'s friends said something to him, he said that this guy had said that the reason S₁'s in the condition he's in is because of drinking or something like that. S₂ says that that pretty well, he was going to kill him and the only reason he didn't was because his friend started coming back. So S₂ was ready to go to his house and he was going to go to his door and ask him like, this made S₂ very angry.

259. F says that this business about S₂'s, see he can understand S₂. If somebody said to him too "well S₁ had his accident because of drinking" and you know that drinking wasn't involved in this accident at all, that would make him very angry too.

260. F says that people try to rationalize why. He can remember too when S₂'s friend was killed and he mentioned this to somebody at work and trying to think why the other two people survived and he didn't and the other person said well you know very often they don't wear their seatbelts. And F thought "what a vicious thing to say" He says that there's something about being a young male that people want to somehow, if something happens to you, then you got it on there yourself. M agrees and F continues that they just deserve, they just deserve this. They didn't even. [I: *They didn't take enough care.*] F agrees and repeats that they didn't take enough care. F says that was not in their case.

258. S₂ offers another example which occurred at a local gaming establishment where he became involved in an argument while inebriated. Despite fuzzy recollection, S₂ believes he slammed a door in anger on departure which provoked the other person to raise his voice. Later in the evening a friend disclosed that he had overheard intimations that S₁'s demise was related to intoxication. Hearing this, S₂ determined to seek out the originator of that accusation and fatally harm him. The incident was avoided by another physical altercation.

259. F is fully able to appreciate the anger which S₂ experienced on hearing such an accusation about S₁.

260. In trying to comprehend the emergence of such comments F proposes that the uninjured try to rationalize how this occur. With reference to the death of S₂'s friend, F recalls a colleague suggesting that the friend must have erred or been remiss in some way. F finds such comments malicious. He observes that when misfortune befalls a young male it is often construed in terms of carelessness and therefore deserved. He notes that was not their case.

261. Also F is aware too that young guys go out for a good time and they sometimes in a ? do dumb things. But they are young guys and they are doing exactly what young guys are supposed to do. And maybe because of what's happened he thinks about this more often. If some, a bunch of young kids were out this one time and took a swing at his mailbox with a baseball bat it would have made him very very angry but now there's a side of him that says "you know, well you know young guys". You know and just out for a good time, he means it still makes one mad but somehow.

262. M says to S₂ don't you dare. F continues that young guys are supposed to do stuff like that, they're not supposed to be goody two shoes all the time and so he understands that. Maybe he was such a goody two shoes himself but somehow that's the right thing for young men to do. But don't EVER accuse them of bringing something on themselves when they didn't do that .

263. F continues that as he said before that he said to S₂ and he said to S₁ too, you know, God forbid whatever happens to you but please don't make a habit because you did something absolutely stupid and M adds that you 100% knew better.

264. S₂ says that people say alot of stupid stuff, they piss him off because sometimes people say something and he sort of wishes that something bad would happen to them so that maybe they'd understand.

261. F acknowledges that young males tend to be prone to engaging in foolish activities. Because of their own experience F finds himself thinking of this more often. He is now more inclined to consider some foolish behaviour as mischievous and anger notwithstanding, to attribute it to pleasure in pranks.

262. M admonishes S₂ against such activities while F posits that young males are not supposed to always adhere to a safe and careful route. While he himself may have been cautious, F is able to accept such behaviour but he firmly reproves those who would lay unwarranted blame on the victims.

263. F had told his sons that while he hoped they would be spared serious difficulties he sternly admonished them to avoid at all cost negligent behaviour. to which M adds, behaviour whose negative consequences are comprehended.

264. S₂ joins in and adds that people who make inappropriate comments anger him to the point of wishing a misfortune would befall them so that they might (appreciate the situation better) understand.

265. S₂ continues that he knows, he remembers, he was just saying to F outside that when his friend was killed, his boss' girlfriend works at the bank in [the nearby town] and S₂ guesses she was saying that X's mom had come in and just sort of made a comment that she looked like terrible. S₂ says he thought that was a stupid thing to say, like she just lost a son. M adds what do you expect her to look like and S₂ continues that she never said nothing about, boy she must be really in a lot of pain, it was more like.

266. [i: *So that's the type, being more sensitive, more aware of meeting people.*] F agrees. [i: *And also probably aware of how insensitive other people are, how they just trip along their merry way. The discrepancy just is more than you can tolerate.*]

267. F says that when you see other people they just go on their way but that's just the way it is too. All these people, its not because they don't feel for what's happened to your son or what's happened to your family, its just that we all have our own lives to live and you can't bear everybody else's burdens on you shoulder. So there's some of that.

268. F says that some people are just insensitive and uncaring.

269. F says he thinks back to himself too. Years and years ago this gentleman that's retired right now, he had a daughter that was killed in a car accident. She was coming home, she was going to school in [a far-off city], she was going to college there. She was coming home and she got killed in a car accident and he can remember never saying a word to him.

270. F continues that the reason he didn't was because he had sons himself and "oh my God, this is just terrible this would happen to her". F says he didn't know how to phrase it so he ended up never saying anything to him about it.

265. S₂ cites an example following the death of his friend when a person made an insensitive comment about the appearance of the deceased's mother. S₂ wonders at the lack of empathy and failure to recognize the suffering.

266. I reflects that they seem to be more sensitive to others as well as aware of the insensitivity of others who are oblivious to those in distress.

267. F recognizes that in the normal course of events most people live their own lives. Failure to empathize with the plight of others is more likely due to the fact that people have their own concerns and simply cannot shoulder the burdens of others.

268. However there are some people who are insensitive and uncaring.

269. F recalls a personal experience many years before where an older colleague had lost a college-aged daughter in a road accident and he had said nothing to him.

270. F attributes his silence to the fact that though he could well appreciate his colleague's remorse, he had sons and therefore felt inadequate to express his condolence and so chose to remain silent.

271. F says that the only thing he is glad, one time, it was at Christmas time and a bunch of them from work had gone out and somebody suggested they go to some bar where they had strippers. And okay, they'll go ahead and do that and him saying "well I think I'll bow out, its a little bit too early". This was in a year of his daughter being killed and it hit F right off the bat. These were going to be young girls about the age of his daughter and he could see them that way. F says he could just remember reaching over there and just, without even thinking he just reached over and just sort of squeezed his arm because he understood. You know and something like that, one little thing that he showed him that he did feel for him.

272. F says he thinks back now, off and on, and alot of people have never approached him or said anything about it. It could be because they are uncomfortable about it themselves. You know, so he doesn't, just because somebody doesn't mention anything to him about it, he doesn't immediately assume that they are unfeeling. Quiet and silence.

271. F recalls with satisfaction that on one occasion involving a group of colleagues he was able to physically acknowledge his understanding of this person's sorrow. F was able to communicate his feelings for this person with a small gesture.

272. F now realizes that many who never acknowledged their tragedy to him personally may have been uncomfortable to express their concern. As well, the absence of direct communication may not be indicative of lack of feeling. All are quiet, there is silence.