

WHAT IS THE MEANING OF RECOVERY
AS LIVED BY PERSONS WITH
TRAUMATIC BRAIN INJURY?

by

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ABSTRACT

To understand the meaning of recovery from traumatic brain injury (TBI) this study sought the perspective of persons living the experience. Each participant was engaged as a co-researcher to make sense of this complex phenomenon. A multiple case study approach was used and seven adults volunteered to share their stories over two interviews. The study produced seven narrative accounts which were the joint product of focused conversation and an explicit, mutual goal. To address the influence of the interviewer, narratives were examined and validated by the participants and by an independent reviewer to ensure they were accurate and complete.

Themes emerged through detailed and rigorous analysis of the interviews and narrative accounts. Adherence to protocol, reviews and consultation assured valid results. Themes were compared across accounts and a cyclical and dynamic pattern took form. It incorporated themes of trauma, deconstruction of a previous life story, reconstruction of a new life story and recovery. These themes were interwoven across four streams of life. One was an internal, deeply personal and emotional experience. Another involved external reactions to the events around the person. An interpersonal stream addressed relationships and an intrapersonal stream referred to sense of identity.

The results of this study challenge structured stage models described in rehabilitation and brain injury literature. Rather than following clearly-defined steps, the co-researchers described turbulent spirals of trauma, destruction and renewal. Popular theory expounds acceptance and adjustment as a final stage in recovery. The results of this study suggested that the battle to attain such resolution is fought earlier in the story

of recovery.

Practical implications apply to treatment program design and to individual and group counselling with persons with TBI. The role of the counsellor is crucial to creating a more conjoint approach to treatment. Events which serve to deconstruct and/or reconstruct life stories can be understood collaboratively and constructively in the counselling relationship. The individuals in this study valued empathy, validation, comprehension and control within a treatment plan which maximized recovery potential by assisting them in defining and attaining personal, social and vocational goals.

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Finally, all of my academic accomplishments were made possible by the support and sacrifices of my husband, Gary. All success I share with him.

DEDICATION

For my Mother

and

For Gary

with love

CHAPTER I

INTRODUCTION

Purpose of the Study

This study explored the meaning of recovery as it is experienced by persons who have traumatic brain injuries.

General rehabilitation models have been shown to be insufficient for addressing the unique course of recovery with traumatic brain injury (TBI), the personality changes which affect behaviour and coping ability, and problems re-adjusting to community living (Wood, 1989). Researchers and clinicians cite cognitive deficits and self-awareness problems on the part of persons with TBI that impede interpretation of study results as the reason for not relying on the views of the person with TBI (Condeluci, Ferris & Bogdan, 1992; Prigatano, 1987). Family members have been shown to perceive experiences differently than their loved one (McKinlay & Brooks, 1984) and to have difficulties in coping with their own emotional reactions to the significant life changes brought upon them by the injury. Both groups assess events from an outsider's viewpoint (Dembo, 1964, 1970) and few studies specifically seek the perspective of the person with the injury (Condeluci, Ferris & Bogdan, 1992; Karpman, Wolfe & Vargo, 1986; Willer, Allen, Liss & Zicht, 1991).

'Meaning' requires the individual's perspective. Without it, we are not in a position to 'assign meaning'. The focus in this study was not on the accuracy or objectivity of insider reports but on the experience through which people with TBI are living, embracing their subjectivity and including deficits which may hamper their ability

to assess their difficulties. Chelune & Moehle (1986) described the utility of self-reports and the frequent discrepancies between reports of the patient, and those of the relative. They argued that it was not the validity of the self-report that mattered, but rather that the "discrepancies provide a rich source of information concerning the patients' view of themselves and of their immediate social environment" (p.507).

Rationale

There is growing recognition that counselling forms an important component of a rehabilitation treatment program for survivors of traumatic brain injury (Cicerone, 1989; 1991; Morris & Bleiberg, 1986; Prigatano, 1986, 1987, 1991). Lezak (1986, 1987, 1988, 1989) has written extensively on TBI survivors' psychological and psychosocial problems in the context of family and community. She targeted the need for education, counselling and emotional support to manage behavioural problems that are both direct and indirect consequences of brain damage and which impede normal social interaction. According to Kay & Silver (1989):

Psychotherapy is often a crucial part of rehabilitation. Head injured persons who are unaware of their limitations will resist many rehabilitation efforts. In addition, head injured persons are often isolated, lonely, frustrated, and depressed. Especially in minor head injury, when no disability is apparent, such persons are often seen as candidates for psychotherapy from psychiatrists, clinical psychologists, or social workers. Very often, however, head injured persons do not improve in traditional psychotherapy (especially if it is psychodynamically or analytically oriented), because their disordered lives are the products not of inner emotional conflicts but of impaired cognition and organically based behavior problems. In fact, if the psychotherapeutic approach gives free reign to all thoughts and feelings, many head injured persons become worse as structure is removed and they become disorganized.

Psychotherapy can help head injured persons come to terms with their changed lives and need for revised goals, but only if the therapist has an acute awareness of how the client's cognitive deficits limit the capacity for self-analysis and

expression, and only if the therapist adopts an active, structuring, supportive, goal-oriented approach. Many clinically trained neuropsychologists have developed a blend of therapeutic approaches that ranges from cognitive/educational to more traditionally psychotherapeutic. In our experience, the head injured patient's capacity to engage in psychotherapy increases as cognitive impairment issues are identified, sorted out, and dealt with (p.152-153).

This emerging acceptance of psychological counselling puts the responsibility for its effective employment firmly in the hands of the counsellor. The research indicates that the client with TBI can no longer be dismissed as inappropriate for, or unable to benefit from, counselling which seeks to heal affective sufferings and impaired sense of self. It plays the equally important role of providing guidelines for the clinicians who seek to treat the "disordered mind" and the "wounded soul" of the person with TBI (Prigatano, 1991, p.3).

The past two decades have marked tremendous progress in life-saving medical procedures resulting in greatly increased numbers of survivors of TBI (Diller, 1987; Long & Williams, 1988), and a proliferation of multidisciplinary programs has emerged. However, current research has yet to identify which aspects of rehabilitation are essential, leaving practitioners to rely on impressions from clinical experience regarding the key elements of an effective treatment plan (Trexler, 1988; Wood, 1989). Quality of life issues, attention not just to physical but also to cognitive and emotional determinants of personal and social competence, become central (Levin, Benton & Grossman, 1982).

Counselling in this field requires current knowledge of the neuropsychological research findings, cooperative liaison with family members and a clear sense of the experiences and goals of the person with TBI. By exploring that which is lived by the person, and that which may be common to persons with TBI, this research aimed to

discover what recovery means to those most directly affected by its presence or absence.

Theory follows from the observation and comprehension of lived experience. The fact that the experiences of persons with TBI has not been explored in depth suggests a gap in the theory applied to personal rehabilitation and career development.

Strengthening the theories applied to rehabilitation of persons with TBI can promote evaluation of programs designed to meet the specific needs of each person and of the traumatically brain injured as a group.

Research Strategy

I strongly believe that to arrive at knowledge relevant to life, instead of selecting scientific topics for their theoretical importance, we must deal theoretically with problems of concern to people in everyday life. If life problems do not fit existing psychological theories-too bad for the existing theories-a new theory will have to be developed. At the very inception of research, in selecting a problem, the merger needed between the scientific quest and life problems has to take place. The use of scientific knowledge requires the introduction of life problems at the very start of psychological investigations (Dembo, 1977, p.14).

When studying questions of current phenomenon in a real-life context, case study research is recommended (Yin, 1984). Using a multiple case study form of empirical inquiry, each case study is regarded as an experiment. Multiple case studies follow replication logic and can be considered more compelling and robust than single case study (Yin, 1984). Multiple case studies approach objectivity and increase credibility. Thus it can be conceived that the power of the methodology emerges from the commonalities of experiences across case studies.

Collection of data is done in an interactive and collaborative manner. The research interview (Mishler, 1986) aims to elicit each person's story in depth and detail. The result is narrative accounts of individuals' experiences of recovery following TBI.

The trustworthiness of these accounts is supported by the rigor of the interviews, assuring free and open disclosure without distortion, deletions or additions, and by the commonalities. The lived events and the meanings the participants attach to them represented the primary interest of this study.

The interviews were intended to produce rich and detailed accounts which were not subject to interview bias. The interview did not involve hypothesis testing but rather a desire to understand the nature of the participants' experience of recovery and its meaning to that person. The interviewer, with ten years of clinical experience, utilized counselling interviewing skills such as attending, listening, clarifying, paraphrasing, and primary empathy to facilitate disclosure and to demonstrate respect for, and understanding of, the experience of the participant.

The research product was detailed narrative accounts of the personalized meaning of recovery with TBI. Each story was presented as a single case study. In addition, accounts were compared with one another to determine whether there are any common patterns or themes.

Definition of Concepts and Terms

In the writings on loss and recovery in rehabilitation in general, and traumatic brain injury in particular, certain concepts and terminology are encountered. The following section describes the manner in which they will be applied in this investigation.

In agreement with the position taken by Wright (1983), I will employ the terms person with a disability or person with traumatic brain injury in this study. This supports the notion of treating the person as central, rather than labels which highlight the

disability.

Throughout the brain injury literature, the term survivor is prevalent while the term victim appears more frequently in earlier writings. Those terms will be employed when referring to such sources. However, I will avoid the using survivor or victim in my own writing and, as mentioned above, will refer to a person or individual. It has been suggested that the psychological impact of being labelled a victim or a survivor is associated with feelings of hopelessness and helplessness. Lew (1990) grudgingly employs the latter term for lack of a satisfactory alternative but states that survival must be seen as a temporary state, that "the recovery process is one of learning to live a satisfying life - to thrive instead of merely survive" (p.7).

Traumatic brain injury occurs when sudden acceleration, deceleration or angular forces cause the brain to move within the skull. When the head hits an object, the brain is thrown against the bending skull causing bruising and tearing of the brain tissue (a coup injury). The brain then bounces back, scraping along the sharp edges on the lower surface of the skull, causing further lacerations and bruising (a contrecoup injury). These forces also set up shearing action which damages the deep structures of the brain, upsetting its delicate balance. The damage inflicted can worsen still with secondary effects. These may include blood loss, impaired oxygenation, bleeding and swelling within the skull, and infection. Depending on the severity of the injury, TBI can damage every aspect of brain function including life-sustaining regulation of breathing and heart rate plus physical mobility, sexual function, memory processes, mood, behaviour, initiative, ability to produce and comprehend speech and ability to concentrate and to

abstract, to name just a few. The damage is globalized and variable. Traumatic brain injury is distinct from penetrating or open head injuries (such as gunshot wounds) in which the damage can be more localized and the deficits more predictable. However, Lezak (1983) recognized similar impairments of memory, concentration, attention and mental slowing to those caused by the damage following TBI, suggesting that some penetrating wounds create similarly widespread deficits. Acquired brain injury is a term which has recently become more widely used and which includes both closed and open head injuries. The term 'head injury' is no longer considered to be synonymous with 'brain injury' as it does not signify damage to the cerebral cortex.

Diagnosis and prognosis is established in hospital from CAT scans and MRI technology, by using the Glasgow Coma Scale (Teasdale & Jennett, 1974) and via post-traumatic amnesia (PTA). The Glasgow Coma Scale measures level of consciousness from three elements of response: eye opening, motor response and verbal response. Motor responses are assessed by both response to verbal commands and response to painful stimuli. Responses are ranked on a scale from 3 to 15. Scores range from 5 or less (very severe), 8 or less (severe), 9-12 (moderate) and 13-15 (mild). A score of 9 means the patient is out of coma. The post-traumatic amnesia (PTA) period ends after coma and after the period of disorientation. This is assessed by the patient's ability to consistently remember events, demonstrating restoration of continuous awareness. The brain injury is considered mild if PTA is less than one hour, moderate if it lasts one to twenty-four hours and severe if it extends over twenty-four hours. The length of PTA is regarded as an indicator of eventual recovery (Jennett, Snoek, Bond & Brooks, 1981;

Wedding, 1986).

Disability refers to limitations of functioning resulting directly from physical damage to some part(s) of the body system. Physical disability has been defined by the World Health Organization (1976) as "an existing difficulty in performing one or more activities which, in accordance with a person's age, sex, and normative social role, are generally accepted as essential components of daily living, such as self-care, social relations, and economic activity". Martin & Gandy (1990) specified impairments may be:

1. physical, affecting ambulation, coordination, speech production, vision;
2. mental, affecting ability to think, remember, comprehend, or general learning ability;
3. social, affecting ability to communicate and establish relationships with other people;
4. emotional, affecting self-image, self-acceptance, mental health; and
5. occupational, affecting vocational or homemaking ability (p.38).

Wright (1983) pointed out that a 'disabled person' is typically more able than disabled and that from a psychological perspective it is important to use the awkward, but more accurate, terminology 'person with a disability'. In concurrence with this argument, the present author will use that descriptor except when referring to the writings of authors who have made other choices. Martin & Gandy (1987) agreed, citing the medical history of the term "disabled" and its inaccuracy regarding the functional abilities of the individual.

The term handicapped also has various meanings. For the purpose of this study it refers to the interference of some activities caused by the disability itself and by the disability in relation to environment or subtle societal attitudes. For instance, a person confined to a wheelchair may be handicapped with regard to dancing, but not with regard to singing. Handicap is also used to describe environmental factors that impede ability. The individual in a wheelchair is capable of going to work but may be handicapped by lack of accessibility to public transport. Lastly, the same person may be handicapped by the attitudes of others. Henderson & Bryan (1984) reported that people with disabilities were considered by the general population to be totally impaired, inferior, less intelligent, in need of charity and preferring the company of other people with disabilities.

Rehabilitation for TBI is complicated by the variability in recovery of similar types of structural damage indicating that neurological and non-neurological factors affect the process (Prigatano, 1987). Researchers have documented the impact of the emotional and behavioural sequelae which are both direct and indirect consequences of brain damage and which impede normal social interaction (Goethe & Levin, 1984; Jennett, 1990; Lezak, 1986, 1987, 1988, 1989; Wood, 1987). Personality changes, emotional distress, and the behavioural problems of a person with TBI are rarely attributable solely to the primary injury or to secondary reactions to impairment or loss. They are the product of extremely complex interactions involving the neurological damage, current social demands, previously established behaviour patterns, access to resources and treatment programs, and the individual's ongoing reaction to all of these (Diller & Ben-Yishay, 1987; Lezak, 1983). Ragnarsson, Thomas & Zasler (1993) agreed

that recovery following TBI is prolonged and variable. They compared the rehabilitation needs of those with TBI and others who had suffered spinal cord injury. They concluded that the variability in symptoms and length of recovery time meant that the TBI program had to offer a wider range of services and be more individually designed.

One of the confusing features of the rehabilitation literature is the multiple use of the term recovery. This stems from the expansion from a purely medical definition to a more expanded, holistic notion of recovery which encompasses quality of life issues. Improved medical intervention has led to higher survival rate following TBI and the field of rehabilitation has had to proceed in the absence of clear understanding or an accepted theory of recovery. Lezak (1986) pointed out that clinicians use the term recovery to refer to improvement, whereas the layperson may understand it to mean return to normal. For the purpose of this research I will differentiate between the state of recovery, a return to normal, pre-injury functioning level, and the process of recovery. The latter is being employed to describe an experience of variable length in which a destination, if it is achieved, is not the point of origin. Wortman & Silver (1987) refer to it as reconciliation with a changed situation which is uncontrollable. Parker (1990) differentiated between recovery as the process of healing and outcome defined as "an interaction between deficits, morale, social support, and the demands made on the person" and which signifies "the status of the TBI victim after a plateau has been reached" (p.18).

The rate of recovery, its extent and pattern vary according to the extent of the injury (Hall & Cope, 1985). Recovery is a naturally occurring healing process which is

influenced by medical and demographic factors and varies over time (Mateer & Ruff, 1990). Finger, LeVere, Almli & Stein (1988) considered the sources of the controversy surrounding the meaning of recovery, identifying:

(1) how little we know about the "functional organization" of the healthy brain, not to mention the damaged brain, (2) the observation that there often is great variability in response to brain damage, (3) the difficulties involved in showing that specific neuronal changes are causally related to recovery phenomena, and (4) the fact that we really cannot "prove" that recovery has occurred. A related fifth issue is the general lack of agreement on how the term "recovery" should be defined (p. 352-353).

Spontaneous recovery refers to the healing of damaged brain tissue. It is indicated by the return of a lost function via the original functional system, not by the development of a different system or by compensatory strategies (Gouvier, Webster & Blanton, 1986). Functional recovery means that a particular skill or behaviour, lost following injury, is again achieved. The means by which this is accomplished may be different from pre-injury processes, representing the difference between biologic healing and learned adaptations.

Neuropsychology is the study of brain-behaviour relationships and was primarily diagnostic in nature. It has evolved to include clinical application and intervention (Horton & Puente, 1986).

Cognition refers to "processes involved in knowing, understanding, learning, perceiving, attending, remembering and judging" (Wilson, 1989, p.117). "The basic ability of the brain to process, store, retrieve, and manipulate information to solve problems (Prigatano & Fordyce, 1986, p.3). Brooks (1990) categorized the wide variety of cognitive deficits witnessed following TBI under the headings of disorders of memory,

disorders of complex information-processing (such as attention/concentration) and disorders of perception and communication.

In the following chapter, research in the field of rehabilitation and specific to brain injury will be examined. The traditional rehabilitation models are examined in light of the complexities encountered following TBI. The relatively fledgling efforts in neuropsychology are recognized both for their important contributions and for the controversies and omissions that remain. In particular, the oversights regarding the value of meaning from the perspective of the person with TBI are addressed.

CHAPTER II

REVIEW OF THE LITERATURE

Traumatic brain injury has devastating consequences which can have an impact upon every aspect of a person's life. In the province of British Columbia 6,000 people each year suffer brain injuries. Of those, 600 require lifetime support (Conn, 1994). While it is an injury that knows no bounds of age or socioeconomic level, it occurs most commonly to males in young adulthood. The cost, in terms of lost lives, lost productivity, and health care expenditures is disproportionately high. Thirteen percent of all injuries are brain injuries, but the associated costs represent twenty-nine percent of the total expenditures (Max, MacKenzie & Rice, 1991).

TBI creates personality change, impairs cognitive and behavioural functioning, emotional control, and self-awareness, strains family relations and ends marital and personal relationships, and restricts employment opportunities thus limiting financial independence. Add to this the individual's reaction to the staggering amount of change in his or her personal story, change which occurs without warning, and it is not difficult to understand why Prigatano (1991) refers to the "disordered mind" and the "wounded soul" of TBI survivors.

In this chapter, the notions of loss, recovery and rehabilitation are considered. The first section, Recovery and Rehabilitation, explores factors in recovery and patterns defined by stage theories within the field of rehabilitation. The second section, Loss and Recovery with TBI, examines the types of losses as well as patterns or stages of recovery common to TBI. The third section explains how the present research will be approached.

This approach stresses the need for the perspective of the persons with TBI so that we may understand the meaning which is attached to their experiences.

Recovery and Rehabilitation

The notion of the recovery process in rehabilitation has been evolving from a purely medical and functional model to a more holistic view of the person with a disability. Dembo, Leviton & Wright (1956) made early contributions to the investigation of the personal and social problems of physically disabled individuals. They placed emphasis on overcoming psychological suffering as a crucial component of adjustment to disability and believed it was important "to know what loss means to the person himself, how it affects the opinions and behavior of others toward him, and what acceptance of loss implies" (p.5). The final goal, an acceptance of loss, referred to a process of a change in values, rather than to reconciliation to an unfortunate situation.

While subsequent contributions have enlarged and enhanced the scope of recovery in rehabilitation (Dembo, 1977; Fink, 1967; Henderson & Bryan, 1984; Kerr, 1977; Shontz, 1977; Wright, 1960, 1983) they have also resulted in a semantic complexity which remains unresolved. Over three decades later, Wortman & Silver (1989) argued that current notions of recovery, including return to normal functioning and expected length of the recovery process, required reconsideration. Within this study, the notion of recovery will be limited to those people who have been physically affected by injury or disease. This is not to be confused with the currently popular notion of recovery associated with abuse or addiction.

Rehabilitation is a set of active interventions designed to facilitate emotional,

behavioural, physical, cognitive, vocational and psychosocial adjustment in partnership with maximal spontaneous recovery (Miller & Keane, 1978; Sarno & Sarno, 1991, Stewart, 1985). Granger (1983) suggested that the medical model of rehabilitation seeks to cure whereas clinical settings are designed to care for the individual in a more person-oriented fashion. Similarly, Vash (1994) wrote that the move from a curative paradigm to a multidisciplinary model meant that "specialists contribute to psychosocial healing (movement toward optimal functioning, given residual disabilities) but not to curing (producing physical recoveries)" (p.xviii).

Theory-building in rehabilitation has been neglected (Keith, 1993; Keith & Lipsey, 1993).

Without at least some framework for explaining the nature of recovery or how treatment produces changes, to take two examples, it is not possible to lay out a program of coherent research. Much research concerns specific clinical problems and leaves unanswered many of the cause-and-effect relationships that would further progress in the field (Keith, 1993, p. 13).

He described the model proposed by the World Health Organization (1980) which follows the disease or injury and resulting impairment to the consequences of the loss (the disability) and to the subsequent deficiencies in social role functioning (the handicap).

The weakness, he argued, lies in the lack of understanding regarding the effects of interventions.

Factors in Recovery

Rehabilitation practitioners need guidelines for intervention strategies. Theorists postulate upon the role of crucial factors and the development of identified stages to serve as a reliable guide through the rehabilitation process. Factors in recovery identify

experiences, important in their presence or absence, which serve to facilitate or hinder the recovery process. Personal adjustment and emotional reaction, societal attitudes and environmental conditions, inclusion in significant relationships and participation in work and recreation make up some of the list. Stages are generally described in either medical terms, documenting the process leading to the point at which biological healing is complete, or from a purely psychological perspective in which the emotional and motivational phenomena are delineated. Current research suggests that a new paradigm of healing, grounded in research and multidisciplinary in nature, needs to be considered.

Emotional reaction and personal adjustment to disability. As mentioned above, Dembo, Leviton & Wright (1956) perceived adjustment to disability to be a psychosocial problem. As a result, the forces that impact that process expanded to include the judgments and expectations of others (such as misfortune as value-loss leading to a requirement of mourning). Devaluation by self and others was considered a significant barrier to adjustment, leaving the injured party to cope with personal and social loss. It was proposed that an enlargement of scope of values (viewing the lost values as nonessential and including other personal characteristics within the scope of values; regarding values as asset values instead of comparative values; and considering lost values as a possession rather than a personal characteristic) could facilitate adjustment to loss.

Wright (1960, 1983) expanded on these ideas, focusing on the effect of the social and physical environment and the role of values in psychological adjustment to disability. In particular she returns to the notion of somatopsychological relations, "those variations

in physique that affect the psychological situation of a person by influencing the effectiveness of his body as a tool for actions or by serving as a stimulus to himself or others" (Barker, Wright, Meyerson & Gonick, 1953, p.2). "The somatopsychological relationship involves social-psychological factors that underlie the way disability as a value loss is perceived and reacted to by other people as well as the self" (Wright, 1960, p.6). Spread is the term used to describe the power of a single attribute to encompass the whole, to determine self-evaluation or evaluation by others.

In response to challenges to self-esteem the person may demonstrate "as if" behaviour, referring to the desire to reject disabled-group identification in favour of the majority group. Masking and minimizing of the disability, discomfort with others with a disability and exaggerating a positive trait to compensate for an undesirable trait are maladjustive but important first attempts to adjust. "Gradually and intermittently, the individual may become aware of the strain that nonacceptance of his disability imposes, and of how, in spite of all his efforts to the contrary, his deviation is real and has personal and social effects" (1960, p.107). Facing irrevocable change and loss, the person may experience deep despair, feelings of worthlessness and may engage in suicidal ideation.

To facilitate adjustment, Wright recommended four value changes: a) enlargement of scope of values means considering valuable aspects of life which remain available to the person; b) subordination of physique relative to other values challenges the overrating of one value; c) containment of the effects of disability serves to restrict the effect of spread, acknowledging areas of life that are not disability-related; and d) the intent in

transforming comparative-status values into asset values is to eliminate harmful status comparisons and attend to internally determined asset values. For example, a status comparison may be to believe one walks too slowly (compared to others), whereas there may be a great sense of reward from the asset value attached to the transformation from wheelchair to ambulation.

The notion of requirement of mourning has been challenged (Vash, 1981; Wortman & Silver, 1989) citing case studies which counter this expectation and identifying difficulties separating depressive mood caused by loss from pre-existing psychological difficulties. Wright (1983) described mourning as an experience which ranges from intense suffering to acknowledgement of brief and minor inconvenience. Whatever its extent, she believed that it was a necessary preparation for facing new challenges and life values.

Vargo (1989) cited four reactions detrimental to the maintenance of self-esteem for persons with disabilities. They include: a) Wright's (1960) inferior-status position in which a limitation in one area is spread or generalized to all dimensions of ability and personhood; b) pity, in which the person with a disability is considered a tragic victim; c) overprotectiveness; and d) salutary status position, again a notion presented by Wright (1960) whereby characteristics of the person with a disability are exaggerated or overvalued, the person may be seen to be more courageous, sensitive or stronger than others.

Hardy & Cull (1987) presented intrapsychic dynamics manifested behaviourally in the form of defense mechanisms within a psychodynamic framework. Their model

explored unconscious processes and included denial, withdrawal, regression, repression, reaction formation, fantasy, rationalization, projection, identification and compensation. Similarly, Henderson & Bryan (1984) suggested some common defense mechanisms which may be employed in the population in general and as coping styles for disability: depression, denial, repression, rejection, displacement, sublimation, aggression, dependency, self-abasement, regression, compensation, fantasy and passing.

The extent of psychological distress experienced in reaction to disability has been controversial. Turner and McLean (1989) found that individuals with disabilities experience chronic stress which leads to elevated risk of depressive symptomatology and major depressive disorder. They identified age, severity of the disability, and gender to be particularly salient factors affecting the adaptation process. Henderson & Bryan (1984) also stated that stress was more frequent and more intense in the disabled versus non-disabled population. Roessler & Bolton (1978) reported lower self-esteem in people with disabilities and increased likelihood of introversion, anxiety, frustration and depression. They did not find evidence to support personality types associated with specific disabilities. Another study (Tweed, Shern & Ciarlo, 1988) examined demoralization and suicidal ideation in relation to dependency. They found increased levels of emotional distress associated with reliance on others (severity of disability was considered a function of level of dependency and invasiveness of help needed).

In contrast, Wright (1983) found no support for the assumption that people with disabilities experience or express overwhelming frustration or higher levels of depression or inferiority than their able-bodied counterparts. She suggested that the assumption

leads to devaluating pity. It was argued that people with disabilities alter their goals and values so that oppressive frustration does not occur. If environmental accommodations are also made, these individuals experience a level of frustration similar to that of an able-bodied person. Uncertainty stems from situations which seem unstructured or unclear. If the person does not know whether the task is physically possible, or how he or she will be received by others, anxiety and insecurity may ensue. One must determine whether the source is external or whether it is symptomatic of the person's lack of acceptance of the disability. Self-esteem will be pursued either through self-acceptance or by rejecting identification with the devalued group.

Shontz (1977) claimed that the onset of illness or disability is associated with an increase in depression but this reaction may also be associated with improvement in somatic status. He concluded that there was no support for the assumption that the effect of a disability on personality is proportional to the severity of the disability. This notion was supported by Hardy & Cull (1987) who claimed that "the degree of psychological impact is not highly correlated with the degree of disability" (p.174) but is, in fact, highly personalized. Rather, they reported that adjustment to disability will generally be better if the individual expresses emotional reactions during the onset. They also cited evaluation of the future, and the individual's role in the future, as a key factor in the adjustment process.

One possible explanation for different conclusions drawn from these studies may be connected to the determiner of severity of disability. Turner and MacLean (1989) combined concrete functional limitations with reports on pain and pain-imposed

limitations. This may be an important distinguisher of difference in types of disabilities. Vash (1981) suggested that both time and type of disability impact one's reaction to disability and that other influences include "the types of functions that are impaired, the severity and visibility of the disability, its stability over time, and the presence (or absence) of pain" (p.9). The power of pain to influence feelings and behaviour is well-documented. Thus, it may be important to differentiate between studies in which pain is or is not a prominent factor.

In a study on the perceptions of physically disabled persons regarding mental-health needs, Thurer & Rogers (1984) concluded that mental-health services were lacking and that the need was perceived to be significant. However, their study detailed the responses indicating that disabled persons believed others with disabilities required mental-health services. There was little explanation for the tendency to attribute mental-health problems to others rather than to themselves. The authors postulated a projection of one's own unacceptable feelings onto others. Another explanation could arise from the insider (evaluation of one's own problems) versus outsider (evaluating someone else's problems) perception differences advanced by Dembo (1964, 1970). Wright (1983) describes experiments in which she compared dyads with different types of handicaps. For instance, one person experienced grand mal seizures while the other was impeded by a lack of willpower, one was legally blind without glasses while the other was overweight. This study, performed many times with varying populations, found that participants would consistently rate their own disability as preferable to that of their research partner. Wright stated that familiarity, coping and self-identity factors were

explanations put forth by participants to explain the results.

In summarizing the key factors in the psychological adjustment to disability, Ostby & Leung (1987) concluded that "adjustment to disability is an individualized process and involves a wide range of reactions" (p. 160). They advised that the individual be the focus, rather than the disability or diagnostic category.

Societal attitudes and environmental conditions. The pioneering work of Dembo, Wright and colleagues was based on Lewin's (1935) field theory. He proposed that behaviour was a function of internal processes interacting with external processes. One's evaluation of oneself and others was related to the physical and social environment. Dembo (1964, 1970) stressed the importance of differentiating between the insider and outsider perspectives, the person experiencing versus the person observing or evaluating. Wright (1983) suggested five ways to reduce attribution errors regarding environmental factors: a) consider environmental factors which impacted problems attributed to traits of the person; b) consider the behaviour of the person in different situations; c) the accommodation of needs of a minority group presented in a societally beneficial way are more readily accepted; d) environmental accommodation is as important as personal adaptation; and e) the perspective of the person experiencing environmental restrictions is crucial to reviewing need for change.

Vash (1981) also wrote of the powerful influences exerted by the immediate environment and the broader cultural context. She differentiated between the limitations imposed by a disability and the handicapping imposed by an environment constructed by the able-bodied and the values, expectations, and customs of the society. Physical and

attitudinal barriers encountered in society in general were considered alongside challenges in one's immediate environment. These included financial restrictions, family dynamics, community influences and institutions and agencies. Using a term coined by Goffman (1961) Vash described the "mortification process" encountered in institutions. The individual loses his or her privacy and power, for the convenience of the system. Those who were cooperative in relinquishing control were least likely to assert self-mastery upon discharge. She suggested that this process was prolonged by agencies providing service to people living in the community.

One attempt to reassess the nature of rehabilitation services and return control to the individual was described by MacDonald & Crozier (1992). They advocated a new perspective, "one that is increasingly responsive to consumer needs and preferences and based on a sound theoretical and research knowledge base" (p.237). This consumer-driven model involves working in partnership with the client and acknowledges the pivotal role of family and community. The decision-making process is placed in the hands of the people using the rehabilitation services. It should be noted that this is not a new idea: Wright (1983) devoted an entire chapter to the client as co-manager in rehabilitation.

The role of the environment in adjustment to disability does not appear to be a controversial one. Rather, it has been neglected or undervalued. Attribution errors can result which place fault with the person adapting to a disability instead of placing it within the context of physical and societal limitations. The models used by rehabilitation professionals clearly impact the client's sense of control or dependency.

Inclusion in significant relationships. The question that arises from the literature is whether the family represents a component of the rehabilitation process or whether the disability is, in fact, a family experience. Vash (1981) stated that the family is the client. As medical doctors have been criticized for healing the body but disregarding the psyche, she suggested that psychologists should reflect upon the similar fault of considering the client to the exclusion of the family to which she or he belongs.

Wright (1983) emphasized the enlargement of scope of values combined with improvements in external conditions in her psychosocial approach. Family members are personally affected by their vulnerability to attitudinal barriers which are societally entrenched. They are involved as collaborators in the instilling of value change for the family member with a disability (Martin & Gandy, 1990).

With regards to the role of friendships, Vash (1981) distinguished between "being" and "doing" relationships. The latter referred to activities enjoyed together, whereas "being" relationships involved valuing time spent together whether engaged in a particular activity or not. She suggested that "doing" relationships were more likely to be jeopardized by onset of a disability if the preferred activities were no longer viable. These relationships would dissipate or evolve into deeper friendships. "Being" relationships, it was argued, are little affected by restriction of activities and endure.

Participation in community, work and recreation. The importance of this aspect of social functioning is best described by Henderson & Bryan's (1984) theories of opportunity and alienation. The theory of opportunity identified the need for affective association, stability and productivity which comes with conforming behaviour to

majority group roles. Alienation stems from feelings of rejection leading to isolation, lack of productive patterned activities leading to normlessness and frequent failures resulting in powerlessness (p.143).

The meaning of work and the experience of the unemployed person has received much attention in the literature. Holosko (1992) provided a summary of empirically supported consequences which typified the experience of unemployment. They included somatic stress-related illnesses, psychological upset (such as loss of personal identity and purpose, worry regarding the future, depression, guilt and grief), and relationship skills and family dynamics which may be upset by financial pressure and role change. Borgen & Amundson (1984) identified six factors which influenced emotional reaction to unemployment. Attachment to the job (which has been lost), social status, individual personality variables (such as internal/external locus of control), financial situation, social support system and future expectations were keys to the dynamics of unemployment.

Organizational changes are an important component of reducing alienation for people with disabilities. Public education and structural accessibility can reduce barriers and create equal opportunities. Events and facilities designed to accommodate people with disabilities increase the likelihood of their involvement in leisure activities available to others.

Stage/Phase Theories

Stage/phase theories, clinically and/or theoretically based, are presented as predictors of processes which typically occur. As such, they serve to guide the clinician providing treatment. There are two points to be critically evaluated concerning

stage/phase theories. The first concerns the difference between stages and phases in adaptation to disability. Frank, VanValin & Elliott (1987) differentiated between stage theories "which describe discrete processes which are (categorically) exclusive" and phase theories which "describe the onset of loosely organized psychological changes which are not exclusive" (p.44). Kerr (1977) however, wrote of the convenience of employing stage models, providing "the stages are not discrete categories, but points on a continuum" (p.317).

The second issue is the lack of agreement, clinically and theoretically, regarding the accuracy and relevance of stage or phase models. "No clear consensus has been reached among researchers and theoreticians concerning the nature of the adjustment process to physical disability" (Livneh, 1986). There is little empirical data to support stages of adjustment theories but they have nonetheless proven useful to practitioners for conceptualizing the process of acceptance (Henderson & Bryan, 1984).

Livneh & Antonak (1990) claimed that most authors posit stage or phase models. Kerr (1977) described a model of psychological development of stages of adjustment: shock, expectancy of recovery, mourning, defense (healthy, neurotic), and finally adjustment. At this stage the individual was described as psychologically normal, having learned to perceive deficits within a milieu of many characteristics. Vash (1978) condensed these stages into two levels of acknowledgement of disability--recognition of the facts and acceptance of the implications--and a third level embracing disability as a positively valued opportunity.

Livneh et al (1986, 1990, 1991) summarized models of dynamic phases of

adaptation to disability: (a) shock (initial numbness); (b) anxiety (panic-like reaction); (c) denial (initial psychological defenses); (d) depression (full realization of loss); (e) internalized anger (guilt and self-blame); (f) externalized hostility (blaming of others); (g) acknowledgement (understanding the implications of the disability); and finally (h) adjustment (emotional understanding and behavioural adaptation to the changes as permanent). Although presented as atheoretical, Livneh (1986) suggested several theoretical frameworks within which the model could be embedded. These included Maslow's hierarchy of needs (1954, 1968), Horney's neopsychoanalytically-oriented interpersonal theory (1945) and Lipowski's coping model (1969, 1979) to name a few.

Long-term adjustment to acute and chronic illness, physical disablement and loss of loved ones has been investigated by Wortman & Silver (1987, 1989, 1990). They claimed that stage theories have been too readily accepted, leaving those who did not fit the pattern to be labelled pathological. A study of recently injured persons suffering quadriplegia showed much higher self-reporting of positive emotions than expected. They also concluded that persons experiencing depression as a stage of recovery did not adapt better than individuals who did not feel depressed. Finally, they challenged the notion of expected achievement of resolution. They asserted instead that some never accomplish that stage and for others it takes much longer than theorists have predicted.

The question remains, however, as to the patterns of recovery in the larger context of the person's life. How do the personal, intrapersonal, interpersonal, vocational and financial factors influence the course of recovery? The following section explores these questions in the context specific to traumatic brain injury. Many aspects

of disability resulting from TBI are unique within the field of rehabilitation, but as with disabilities in general, each person reacts in his or her own individual way.

Loss and Recovery

Following Traumatic Brain Injury

The process of recovery and rehabilitation after TBI is dissimilar to that of other injuries because the long-term deficits that impair resumption of normal living are cognitive and behavioural rather than physical. In addition, a major obstacle in the quest for a productive rehabilitation outcome is the person's lack of appreciation for the limitations imposed by the injury. As a result, many individuals who suffer traumatic brain injury resist involvement in rehabilitation programs and are reluctant to adjust life goals to match their abilities (Kay & Silver, 1989).

Some difficulties common to persons with TBI include: lack of awareness; communication problems (ex. anomia, receptive or expressive aphasia); attention/concentration impairment; emotional lability; fatigue; executive functioning problems (such as impaired judgement, problem-solving, decision-making and organizational skills); masking (an ability to display a "chameleon-like character", Lezak, 1988); and personality disturbance resulting in social isolation (Lewington, 1993). In addition, this is an invisible disability. This may guard the person from the presumptions or prejudice of others, but it can also lead to confusion or unrealistic expectations on the part of observers, even those close to the person with TBI.

Kurt Goldstein (1942), a pioneer in the field of brain injury, studied brain injuries sustained in wartime. He identified three processes that contribute to recovery of

performance following brain damage: restitution of damaged brain tissue resulting from spontaneous healing processes; reduction of the complexity of situations which might overwhelm the person coping with brain damage; and the learning of new systems to compensate for those which were disturbed.

Since then, and particularly in the 1980s and 1990s, many models have been proposed and it has been suggested that a foundation is being laid upon which clinicians can begin to predict probable recovery process and stages in recovery (Wood & Eames, 1989). Problems encountered in TBI rehabilitation are generally described from the scientist/practitioner viewpoint. The determination of what the stages are and how they should be utilized has evolved from observation by others (medical/rehabilitation professionals and family members).

The outsider perspective (observing and evaluating, Dembo 1964, 1970) has flourished at the expense of the insider's personal experience. It is acknowledged that the individual regards his or her experience with TBI as a story--one which begins with the injury and carries on, either indefinitely or to an identifiable end. Recovery takes place over time. The story has a beginning which is marked by disequilibrium or conflict. This propels the individual to make various attempts to understand and revise his or her predicament. This is the middle of the story. The end is heralded by restoration of a past way of being or by accommodation to a new and unchangeable reality. The following sections address these three parts of the story. In an effort to integrate the research with human experience, I will describe hypothetical characters in each part of the story. For clarity, these fictional vignettes will appear in italics.

The Beginning

The weeks or months following onset of injury are marked by trauma and confusion.

The individual finds himself in hospital, unable to remember past events or process new information. He is frustrated in his attempts to maintain his attention and analyze this changed situation. He may be verbally and behaviourally disinhibited, even aggressive. His thinking is disturbed. Since he does not perceive a problem, he denies needing help and is irritated that others do not agree.

Stuss & Buckle (1992) refer to this stage as the acute period of recovery. He may exhibit great emotional lability (eg., fear, anger) and agitation or become emotionally and socially withdrawn (ie., depression). Another possibility is that he displays persistent lethargy. He may have speech and language disorders that impede communication. Goethe & Levin (1984) call this the transitional period of recovery. It is a time of helplessness, uncertainty and dependency. There is little that makes sense to the brain-injured person in the beginning.

Family members, initially shocked to find him in intensive care, face the possibility of his death. They can fall prey to the "sleeping beauty" myth (Romano, 1974) expecting him to awake and carry on as before. When he survives, but with apparent deficits, they may react with denial. These can include verbal refusals to acknowledge obvious behavioural and personality changes and inappropriate responses, to coping strategies for the disabilities (such as encouraging a premature return to work or mistaking a difficulty in initiating activity for laziness). As a result, he may find support

for his allegations that he is unchanged and thus reject necessary adjustments and interventions. Conversely, he may comprehend and acknowledge his problems but encounter rejection or conditional support from family members unable or unwilling to confront such a reality (Romano, 1974). From the professional perspective, psychosocial problems must be assessed in light of pre-morbid personality characteristics, family dynamics and potential for employment (Bond & Brooks, 1976; Prigatano, 1987; Wood, 1989).

Upon his discharge from hospital, he and his family receive recommendations and referrals for rehabilitation programs. The family listen politely but don't think this will be necessary. They are convinced that his immature behaviour will dissipate once he is back in familiar surroundings. He is surprised to learn that the friend he met on the ward has already begun such treatment: his parents sent him, immediately upon discharge, to a group home offering a rehabilitation program. He thinks his friend must have suffered a much more severe injury.

In summary, according to available research and theory, the individual's story does not begin upon awakening. He experiences brain dysfunction but is not aware of its dysfunctional nature. For example, he may not remember events of the past but be undisturbed by this failure to remember. Over time, however, with recovery of brain function and increasing self-awareness, he begins to experience a sense of significant loss and concern about implications for his future. He may experience feelings of shock and embarrassment when he hears reports of his uncharacteristic behaviour. Current research and theory have focused little on individual experience. Factors such as external

behaviour and impact on the family have been explored. That which constitutes a personal beginning has not.

The Middle

This could be referred to as the working stage of recovery from brain injury. A struggle between hope and hopelessness.

She suffers from fatigue which makes it hard to keep up with others. Some suggest she's not trying hard enough. She has trouble following conversations, particularly if they involve more than one other person. She gets lost in the middle of doing a task. She can't remember what others said, what she intended to do, who she has met before and when she has an appointment. She's been making poor choices when faced with decisions. She doesn't trust herself any more. She finds the details involved in problem-solving too overwhelming.

Once out of hospital, she returns home to her parents. The hospital experience was both restricting and protective. Now she attempts to incorporate a new and uncertain self into old, familiar situations. She tries to return to her previous employment and visit with friends. Her goal is to have life return to normal. However, the presence of personality disturbances and cognitive deficits interferes with the execution of this plan.

Prigatano (1992) described active emotional and motivational disturbances (irritability, agitation, belligerence, anger, abrupt and unexpected acts of violence or episodic dyscontrol syndrome, impulsiveness, impatience, restlessness, inappropriate social response, emotional lability, sensitivity to noise or distress, anxiety, suspiciousness, delusional, paranoia, mania) and passive disturbances (spontaneity,

sluggishness, loss of interest in the environment, loss of drive or initiative, frequent fatigue, depression, childishness, helplessness, lack of insight).

Prigatano & Fordyce (1986) delineated six categories including disorders of attention and concentration, disorders of initiation and planning of goal-directed activities, disorders of judgement and perception, disorders of learning and memory, disorders of the speed of information-processing and disorders of communication. It has been suggested in the research that cognitive factors are more important than physical factors in re-entry to work and community (Wood & Eames, 1989).

Many researchers (Brooks & McKinlay, 1983; Lezak, 1987; Prigatano et al, 1986; Thomsen, 1984, 1989) have explored personality changes (affective and motivational disturbances) which are associated with long-term social isolation. Some assert that recovery is hampered to a greater extent by emotional and personality disturbances than by cognitive or physical deficits (Lezak & O'Brien, 1990).

She goes to work but find herself exhausted by mid-morning. Phone calls and interruptions from co-workers upset her waning concentration. She can't remember what she was working on. Familiar tasks suddenly seem complex and overwhelming. She smashes the radio that filters music through the office. She wonders if her employer and co-workers have been conspiring to replace her in her absence. She takes a trivial comment as proof and quits impulsively. She turns to her friends but they, too, have changed. She used to have fun with them at clubs but now they seem reluctant to go with her. Last time she was escorted out by security. Sometimes she forgets the arrangements they have made and they become annoyed with her. They return her phone calls less

often. Soon her siblings and parents become her only companions.

According to Williams & Kay (1991) the "injured person's process of "recovery" and redefinition of self is both paralleled by, and embedded in, the family's "recovery" and redefinition of itself as an altered family system" (p.xv). The family is often at a loss in coping with the myriad of changes in their loved one and in understanding their own intellectual and emotional reactions. The importance and the complexity of the role of family in TBI recovery is reflected in the numerous research publications devoted to the topic (Brooks, 1991; Karpman, Wolfe & Vargo, 1985; Kosciulek, McCubbin & McCubbin, 1993; Livingston, 1990; Livingston & Brooks, 1988; Rosenthal & Geckler, 1986; Sachs, 1991; Williams & Kay, 1991; Wood & Eames, 1989).

Lezak (1989) stated that behavioural problems pose the most seriously handicapping disorders. She suggested that since many victims are not overtly physically damaged and present well verbally, their behavioural anomalies may be overlooked or misinterpreted by anguished relatives. Wood (1987) stated that behavioural problems can produce deterioration in family relationships and negatively affect rehabilitation efforts. As a result, the individual may experience reduced community support, greater social isolation and restricted levels of independence. Psychiatric disorders, particularly following severe brain injury, hamper rehabilitation efforts and influence recovery prognosis (Grant & Alves, 1987; Prigatano, 1986, 1987; Rosenthal & Bond, 1990; Wood, 1987).

She gets bored sitting at home all day. The doctors suggest different kind of work but she's not going to accept a lower salary than she's accustomed to. It's just a bad

economy right now. She registers for a semester at college. Despite recommendations she starts with a full course load. Soon she finds herself lost, unable to maintain the workload and finding it hard to concentrate in class. Everything just seems to take her longer than it does for her classmates. She thinks she knows the material but can't seem to summon it for exams. She withdraws halfway through the semester.

Return to work is an important goal in TBI rehabilitation (Bostwick, 1993; Wehman & Kreutzer, 1990). It is also complex due to the permanent changes resulting from the injury and frequently encountered reluctance to settle for a lower level of employment (Wood, 1989). Research indicates that without specialized vocational rehabilitation, return to work expectancy is 0-12% for individuals with severe brain injury (Brooks, McKinlay, Symington, Beattie & Campsie, 1987). Stuss & Buckle (1992) referred to the performance inconsistency on repeated assessments found with persons with TBI, compared with uninjured subjects. It was suggested that this variability accounted for poor employment prospects despite apparent competence.

Lezak's (1982, 1987) review of the research and results of her own studies lead her to conclude that "the most significant residual impairments sustained by many head trauma victims are of those functions required for pursuing a course of study or getting and keeping a job, filling in unscheduled and unstructured time satisfactorily, and making and maintaining close social relationships--the executive functions" (1987, p.64).

So she starts going to the bar. It's something to do and there is always someone to talk to. The doctor also told her not to drink alcohol but she figures a little won't hurt and it makes her feel better. She meets some nice guys there. They don't think anything

is the matter with her and she's getting good at covering up when she forgets what they said. It's great to be back in the game. She can't figure out why her friend, the one she met in the hospital, stays home all the time. She doesn't want to see anyone, and guys least of all.

The expression of sexuality could be considered an integration of physical, cognitive and psychobehavioural components (Zasler & Kreutzer, 1991). Sexual dysfunction is common following TBI and affects the individual and his or her family. Problems may include decrease in libido, problems with sexual functioning and reduced frequency of intercourse. Impaired decision-making ability may affect choices of sexual activity and sexual partners. Social isolation may lead to sexual inactivity. Adolescents and young adults may be reluctant to discuss problems with their parents. The strain for married persons living with their spouse is in managing the many stressful factors (ex. guilt, inadequacy, financial concerns, lack of support and professional treatment) while trying to preserve emotional and sexual relationships.

Since she got in trouble with that man, her parents have really clamped down on her. She has to tell them where she is going and when. She doesn't have any money left so she relies on them for cash. There's no use getting up early because there is nowhere to go. She gets up in time to see the talk shows and some soaps. No need to dress up, sweats will do. In fact, she won't bother with her hair either. What difference does it make anyways? When the rest of the family go to bed at night, she's tired but not sleepy. She watches TV until 3 a.m.

Psychosocial problems arise frequently. Low self-esteem, negative body image,

loss of friends, employment, and driver's licence and sudden reliance on family can have a devastating impact on the injured person (Prigatano, 1986; Rosenthal & Geckler, 1986). Social isolation is a frequent outcome of disabilities associated with TBI.

The impact on the family is also long-term. Family members experience high levels of stress for years after the injury (Florian, Katz & Lahav, 1989). It has been demonstrated that family members and persons with TBI differ significantly in their reporting of behavioural changes (McKinlay & Brooks, 1984). Heightened levels of stress and depression plague relatives in the 12 months following injury (McKinlay, Brooks & Bond, 1981; Oddy & Humphrey, 1980). Other studies (Brooks, Campsie, Symington, Beattie & McKinlay, 1986; Lezak, 1987) show family distress lasting five years and longer. Thomsen (1984) found emotional, behavioural and personality changes affecting family functioning 10-15 years post-injury. Social isolation was apparent, both for the individual and for the family. Financial burdens add to the scope of the problem. Generally, family members feel misunderstood, isolated and unsupported (Kreutzer, Serio & Bergquist, 1994; Livingston, 1990).

Lezak (1986) proposed a stage model of family reaction to a brain damaged member. Non-linear and variable with each family, it described family happiness, bewilderment, discouragement, depression, mourning and reorganization. She suggested that those who pass through the mourning stage can then detach emotionally from guilt and anger and redefine their relationship with the injured relative. Brooks (1991) argued that this final stage was too idealized. He pointed out that disengagement in marital families (in which the injured person and the primary caregiver are spouses) was likely

separation or divorce and parental families (in which the injured person is a child, adolescent or young adult and the primary caregiver is a parent) struggle with acceptance, persisting with active care, search for facilities and hope for late recovery.

The experience of the family has been described from the perspective of the marital family (Willer, Allen, Liss & Zicht, 1991) and from that of the parental family (Karpman, Wolfe & Vargo, 1985). In both studies, the researchers asked the participants with TBI, and their spouses and parents respectively, to identify the primary problems and facilitators of adjustment to brain injury. In both studies, researchers commented on the extent of common experiences cited by the participants. Family support was identified as a facilitator of adjustment and a coping strategy in the studies.

Condeluci et al (1992) proclaimed that "with most community issues, the way people know reality is not with data, statistics, or scientific writings but through stories and anecdotal experiences" (p.39). These authors also suggested that persons with TBI want to be seen as people, not as performers of isolated tasks. Theories and research identify a plethora of potential limitations facing each person in this working stage of TBI. Greater comprehension of brain dysfunction has lead to anticipated categorical symptoms and has clouded understanding of the struggle as it is lived by that person.

The strengths then, in terms of current research and theory, lie in the growing body of knowledge surrounding brain dysfunction and its impact on personal and interpersonal functioning. Ironically, the increased body of neuropsychological knowledge may be leading further away from comprehending the individual story. A call for more quantitative research seems to support this trend. The risk becomes one of

symptom-based categorization, ignoring or even rejecting the uniqueness of the person, the story and its meaning.

The End

Adjustment and acceptance are commonly listed goals of rehabilitation (Dembo et al, 1956; Henderson & Bryan, 1984; Kerr, 1977; Prigatano, 1986; Shontz, 1977; Vash, 1978; Wright, 1960, 1983). As with rehabilitation in general, these goals and the ways in which they may be accomplished, are under debate.

Ben-Yishay & Prigatano (1990) report six stages in a holistically oriented recovery process in a treatment setting. Using cognitive therapy, they pursued a hierarchy of distinct stages through which their patients must advance. They elicit patient engagement in rehabilitation activities via interventions which optimize alertness, basic attention and concentration; progressive awareness of the problems, mastery of compensatory techniques for remediable cognitive and personality deficits; control and daily application of these compensatory activities; acceptance of deficits emerges with an aim to a realistic future, releasing pre-injury goals and expectations; and when all previous stages have been attained and the patient has been assimilated back into the community, a new identity emerges. According to the authors, successful completion of these stages indicates restoration and adaptation to permanent traumatic brain injury. Eames & Wood (1989) asserted that their fourth period of recovery (long-term) might extend until retirement or be lifelong.

He stays home with the kids now. He tried the job trials but struggled each time. There was just too much to keep track of at work. Some mornings he felt too low to get

up and go to work. The disability pension isn't a lot but it helps. He and his wife have been budgeting and with her income and his pension, they'll be OK. Buying a house is out of the question, but in a few years when they're back on track, maybe a condo...

He's learned to control his temper better. They're great kids but they can really get on his nerves. Getting them up and off to school each day is exhausting. Often he just watches TV for a while after they're gone. But then he does the dishes and the laundry. The days are long but he still finds it hard to fall asleep at night. Maybe he thinks too much. He can't help it. He feels pretty good about helping his wife with the kids and the apartment. But some of the guys make fun of him, say he's a welfare bum. He believes it's not right for the man to be at home, he should be working like the rest, supporting his family. He's glad he and his wife survived the hard times after the accident and stayed together, but at times he's haunted by the thought that she might have been better off if he'd died.

Prigatano's (1991) reference to the disordered mind and the wounded soul of the person with TBI alluded to the existential questions that arise for people trying to understand the reason for their injury and searching for new goals toward a meaningful life. He suggests that the symbols of American culture--intelligence, beauty, winning and health--must be replaced, for the person with TBI, with the more basic symbols of work, love and play. As described previously, even these more basic symbols represent a significant challenge to attain.

He still finds it helpful to attend the monthly meeting of the head-injury support group in his area. He resisted going for the longest time, but finally agreed when it was

suggested that his wife could go and find support there, too. He felt self-conscious as first, and was worried about getting depressed hearing others' stories. It's better just to face it and carry on without whining about it. It wasn't as bad as he expected, though, and he agreed to return the following month. As time passed, he found himself looking forward to the meetings. Listening and talking to people who understood the difficulties he faced was reassuring. He did not feel so alone. Sometimes he'd get frustrated when he thought about a group member who was working and said she believed the injury was a blessing in disguise. She said she'd discovered a new appreciation for life and the things that really matter. On the other hand, he thought about that young fellow who kept getting in trouble with the police. He was so angry in the meetings and didn't seem to have any friends at all. It just goes to show that everyone ends up in a different place. He wondered what happened to the girl he met in rehab. She was taking college courses and hoping to transfer to university.

Still, it wasn't just the accomplishments that mattered. One person in the group got a big cash settlement and help starting a business, but all he ever did was complain about the way things could have been. He said the meetings were stupid but he came anyway. And then there was that guy who could barely make ends meet. He worked sweeping out an automotive store but he thought he was lucky to have the chance. He goes there early and leaves late. Instead of being bitter, he seems to accept it. He even volunteers at the drop-in centre, talking to other people with head injuries. He says he wants to give something back.

Condeluci et al (1992) reviewed surveys of survivor and family perspectives of

rehabilitation outcome. Survivors stated that self-esteem, self-awareness and social skills were as important to them as learning compensatory strategies and daily living skills. With data drawn from three surveys, the authors concluded that survivors want to live independently managing their own affairs, and have good health and an earned income; even more important are relationships and acceptance in the community; and quality of life issues following TBI are correlated with availability of resources and support in the community. The authors suggest that rehabilitation participants be consulted regarding their own outcome values. These ideas are echoed by Evans & Ruff (1992) referring specifically to rehabilitation outcomes but addressing in sum, quality of life issues.

Current research and theory reflect the belief that individuals must attain acceptance or adjustment. Reassessment of values, both personal and societal, is proposed. Researchers delineate stages or phases of recovery through which the individual will proceed to enlightenment. On the other hand, according to Banja (1992, p.114), "misfortune can be overcome, but tragedy never can. It can only be accommodated. We can only make room for it and find ways to tolerate its obnoxious presence". Could there be a bias inherent in the researcher/clinician's expectation of resolution?

Condeluci et al (1992) turned to the individuals with TBI to determine their values regarding treatment outcome, but I found no documented evidence that this approach has been implemented to discover their own meaning of recovery. What does a new identity mean to that person? What does it mean if one does not achieve acceptance of the injury? What markers does the person consider significant in the recovery process? The

value of the answers lies in their being elicited rather than imposed. I anticipate that the end of the story as described by each person will offer depth and complexity which is not so much a departure from the literature as an enricher and an identifier of meaning.

Within medicine, rehabilitation and neuropsychology, tremendous strides are being made to enlarge the body of knowledge related to brain function. The shadow side of this progress is the risk of relying too heavily on scientific data and statistics and losing sight of the unique person and story. Stages of recovery are depicted in the literature and treatment programs are offered in the community without a clear understanding of the meaning of recovery to the person with TBI. This appears to be a significant omission.

The review of studies of recovery from TBI suggests that central themes in the story may include self-esteem enhancement being as important as relearning of daily living skills; family support and involvement in the recovery process; maintenance of pre-injury friendships; attendance to the individual on a personal and emotional level as well as a practical one; acceptance or adjustment to irrevocable losses and compensatory systems; and ability to attain new directions or reconnect with an original goal.

Approach to the Research

The study of recovery from brain damage is controversial and has been so for 150 years. It has been suggested that the 1980s saw a significant shift from focus on physical recovery to a broader definition of what it really means (Wood, 1990). The call for a multidisciplinary approach now has researchers attempting to address the organic, cognitive, behavioural, emotional, motivational, environmental, vocational, economic and social aspects of the disability, the complex interaction of these different factors, and

determination of the factors that promote or impede recovery (Prigatano, 1988; Slavin, Laurence & Stein, 1988; Wood, 1990; Wortman & Silver, 1989).

Acknowledging the crucial and ever-present connection between theory and practice, Finger et al (1988) pointed out that:

For the patient, it will probably matter little if one or many biological events are responsible for recovery of function or whether one can or cannot "prove" a particular hypothesis. The victims of brain or spinal cord injury only want to know if the quality of their lives will improve and if a return to a productive and independent existence will be possible. Over the last few decades the rapid advance of research in the neuropharmacology, anatomy, and behavior of brain-damaged subjects has moved us to the stage where we can begin to intervene effectively to modify some of the effects of CNS injuries. Thus, although there are sources of controversy that may persist, there also are reasons for optimism, especially when broader and perhaps more important questions are asked about brain damage and the potential for "meaningful" improvement (p.360).

The question arises regarding what meaningful is from the individual's point of view.

Theory follows from observation and comprehension of lived experience (van Manen, 1990). The fact that the experiences of persons with TBI have not been explored in depth from their own perspective, and as a process which evolves over time, suggests a gap in the theory applied to personal rehabilitation. What are the qualities from a personal, holistic viewpoint, which make life worth living? The aim of this research is to give voice to those for whom recovery is crucial, central and personal. If we are to seek answers to the question of recovery, their views must be elicited, valued and applied.

This approach has not been widely employed in the field of brain injury.

Researchers' methods of assessment of personality disturbances include standardized tests, structured interviews with the patient and an informant, and self-report inventories.

Utilization of patient self-report is considered problematic due to awareness deficits

(Prigatano, 1987). The extent to which the patient is in agreement with the informant is viewed as a marker of patient insight and psychosocial progress and a predictor of future functioning level (Chelune & Moehle, 1987; Grant & Alves, 1987; Lezak, 1983; Prigatano, 1986). Research suggests that relatives may be more sensitive to some deficits and more resilient to others. Their reports may vary significantly from that of the family member with TBI (Bond, 1975; Brooks, 1984; McKinlay & Brooks, 1984; Thomsen, 1984). The emphasis is on functioning as observed by others. There is no question that the ability to behave according to social norms will greatly influence the adjustment to society following TBI (Lezak, 1983; Prigatano, 1986).

In their exploration of the problems and coping strategies of individuals with TBI and their spouses, Willer et al (1991) concluded that "the clear description of problems and coping strategies presented by the men and women with TBI suggest that they have greater insight into their problems that previously reported. Their opinions and perspective should be included in future TBI research" (p. 464). Condeluci et al (1992) explored outcome and value from the survivor's perspective and suggested that "the perceptions and feelings of service recipients regarding outcome and their value are as valid as other measures of outcome more commonly performed" (p.38). They posited that different groups (payers, families, professionals and survivors) seek different outcomes. Payers and professionals may look to functional, tangible gains while families and survivors may find intangibles such as happiness and autonomy to be equally important. Karpman, Wolfe & Vargo (1986) explored the psychological adjustment of adult TBI survivors via exploratory interviews with them. Themes of importance for the

people with TBI included memory loss, social isolation and uncertainty about the future. Their parents shared concerns about overprotectiveness, financial problems and emotional strain (p.32).

Lived meaning "refers to the way that a person experiences and understands his or her world as real and meaningful. Lived meanings describe those aspects of a situation as experienced by the person in it" (van Manen, 1990, p. 183). From a phenomenological perspective, it is not the factual accuracy of the account that matters but rather the nature of the phenomenon, with its many layers and dimensions, as a possible human experience. In a call for reliable, meaningful global outcome measures, Evans and Ruff (1992) stated that: "Meaningfulness is assessed by surveying the perceptions and opinions of the consumers/recipients of rehabilitation services as to the short- and long-term contributions that the effort itself has made, or is likely to make to the individual's long-term functioning" (p.30). Currently, the process of recovery, the story of a person's experience through that journey remains hidden and uncertain, the results vague and ill-defined. The purpose of this study is to attempt to understand the meaning of the lived experience of recovery from TBI.

CHAPTER III

METHODOLOGY

This research is phenomenological in nature. It is a study of lived experience. It employed a multiple case study design. Interviews elicited the experiences of the participants which were organized into story form. Themes generated from the data demonstrated common experiences across participants. The number of participants included in the study was determined by the point of saturation. In other words, once the pattern was clearly repeating itself in the stories, no further participants were sought. "Formal research should look toward informal ways of coming to understand people in order to learn from their wisdom" (Howard, 1986, p.40).

Phenomenology

This is a phenomenological study which addresses the research question by constructing narrative accounts drawn from interviews within a multiple case study model (Yin, 1984). Phenomenological research investigates and legitimizes the human inner experience. It is the study of lived experience (Colaizzi, 1978; Osborne, 1994; van Manen, 1990). As a philosophical perspective, it explores how people experience, describe and interpret phenomena. "Anything that presents itself to consciousness is potentially of interest to phenomenology, whether the object is real or imagined, empirically measurable or subjectively felt" (van Manen, 1990, p.9).

"There is no separate (objective) reality for people. There is only what they know their experience is and means. The subjective experience incorporates the objective thing and a person's reality" (Patton, 1990, p.69). According to Osborne (1994):

Phenomenological methods attempt to explore conscious experience directly through a specialized form of introspection rather than inferentially through overt observation, as does cognitive science. Exploration of the inner worlds of experience by phenomenology enables researchers to reclaim that part of human being that has been so long neglected due to the prevailing view that human science must be natural science (p.168).

Howard (1986) challenged psychologists to develop a human science, one which appreciated the nature and dignity of humans. He cited Carl Rogers' stress upon the meaning, not just the statistical significance of results, to embrace creative speculation and phenomenological thinking, and to respect the subjective human being participating in the research. He referred also to Giorgi's guidelines for phenomenological research including a clearer connection between the experimental and lived situation, attention to the presence of the experimenter, and relevance.

This study follows the phenomenological tradition of pursuit of understanding of experience as it applies to recovery for persons who have suffered brain injury. The purpose is also to test "the assumption that there is an essence or essences to shared experience" (Patton, 1990, p.70). This research seeks to determine if there are essential experiences which contribute to a mutually assigned meaning to recovery from TBI.

Narrative

Narrative is "an organizational scheme expressed in story form" (Polkinghorne, 1988). According to Angus & Hardtke (1994) narrative is applied "to conceptualize the processes entailed in generating explanations of everyday events and organizing these experiences into a coherent self-identity or life story" (p.190). In qualitative analyzes, themes are generated from the data collected in the interviews. Independent reviewers assess the themes delineated and refined by the researcher. These themes are then

reviewed with the participant for accuracy.

Karpman et al (1986) employed similar methodology to the one described here. They explored the process of psychological adjustment of persons with TBI and their parents, and reported rich and detailed accounts. From these they identified several themes within each group and generated hypotheses.

Case study

Multiple case study is a distinctive form of empirical enquiry in which each study is regarded as an experiment. It is considered to be more robust than the single case study due to its replication logic (Yin, 1984). Commonalities across individual cases strengthen the trustworthiness of the results.

Descriptive case studies are exploratory in nature. The purpose is to discover what is, rather than to support or negate a pre-conceived hypothesis. However, there are problems inherent in the researcher's role in the interviewing process. The potential for bias must be recognized, efforts taken to minimize its effects and its influence evaluated in the analysis.

Other problems common to case studies and research interviewing have been widely debated (Campbell, 1979; Mishler, 1986; Polkinghorne, 1988; Yin, 1984). Although qualitative research is now generally accepted within psychological research circles (Campbell, 1979) its limitations, like those of any other method, must be considered. Yin (1984) employed Kidder's (1981) four design tests to address problems of internal, external and construct validity and reliability. Mishler (1986) urged the researcher to support more than the recognized threat to internal validity. He posited that

the plausibility of an interpretation in light of rival interpretations depended upon the rigor of the interviewing process and its documentation, the outlining of the rules guiding analysis and a theoretical framework, and the opinions of the participants and others regarding the plausibility and meaningfulness of the interpretations. The challenges to the multiple case-study design were addressed by responding to the recommendations as follows:

Construct validity refers to the correct use of operational measures. The changes studied in this investigation were the subjective experiences of recovery from traumatic brain injury. Yin (1984) suggested that these changes be measured in the case studies by using multiple sources of evidence. This was not the case in this investigation, for reasons outlined in the rationale for the study. The vast majority of the literature regarding recovery from TBI ignores or minimizes the perceptions of the injured person. The purpose of this study was not to test the accuracy of their opinions but rather to respect the subjective experiences of the person regardless of others' perspectives. The study aimed to establish a chain of evidence: a) by having participants review drafts of the report in the composition phase; and b) by inviting external observers to follow the derivation from the research question to the case study's conclusions.

Internal validity does not seek an absolute truth but requires that the accounts be plausible (Mishler, 1986). Each account should be believable, with no other interpretation of results likely. Threats to internal validity were met in this study by conducting pattern-matching analysis and by having accounts reviewed by participants and an independent judge to assure accuracy and to address meaningfulness and plausibility.

"Scientific quality is not the principal standard; an evaluation should aim to be comprehensible, correct, and complete, and credible to partisans on all sides" (Cronbach, 1980, p.11).

Kazdin (1981) identified common threats to internal validity typically found in case studies. These pertain to mistakenly crediting treatment effects. The current study explores the causal attributes postulated to be meaningful to the participant rather than seeking to promote any experimentally induced effect.

External validity is the extent to which case study results can be generalized beyond the cases involved. According to Yin (1984), "case studies, like experiments, are generalizable to theoretical propositions and not to populations or universes. In this sense, the case study, like the experiment, does not represent a "sample," and the investigator's goal is to expand and generalize theories (analytic generalization) and not to enumerate frequencies (statistical generalization)" (p. 21). The problem of external validity is addressed in this study by using replication logic via multiple case studies and by restricting discussion of the results to the study's population.

The problem of reliability, reducing errors and biases in the study, was handled in the data collection phase using case study protocol which would permit other researchers to repeat the study. The research process involved observing, interviewing, documenting and analyzing. All of these processes were recorded so that the protocol (the rules guiding analysis) and the ways that interpretations were grounded in or related to the theoretical framework, were clear. As further defense against risks to reliability, a case study database was constructed. All interviews were audiotaped in their entirety,

permitting critical evaluation (by the researcher, participants, and independent reviewers) of the transition from raw data to narrative accounts.

Participants

Study participants were recruited through a referral network of professional contacts. They were directed to the study by three psychologists and the friend of a family member of one participant. Each of these referral sources had been informed of the study by the researcher. The initial letter of contact can be found in Appendix A. The participants were selected on the following basis: a) that each had experienced a traumatic brain injury and was no younger than 16 years of age at the time of the injury; b) that each person could reflect upon this part of their lives without undue emotional trauma; c) that each was able to articulate their experiences in a coherent fashion; and d) that each was at least 18 years of age at the time of the interviews. Each prospective participant was fully informed of the purpose of the study and the manner in which it was to be conducted. "If results obtained from subjects treated as informed co-investigators are more similar to the behavior of subjects in non-experimental settings than are data obtained in the traditional manner, it might signal a more satisfactory resolution to some long-standing problems of contamination in experiments" (Howard, 1986, p.24).

To address the research question, participants had to have experienced a traumatic brain injury. As demonstrated in the review of the literature, TBI creates significant life changes which impact almost every aspect of daily living. Each participant was screened to assure some sense of recovery since the onset of the injury, since it was this process which was being explored.

Due to the nature of potential deficits created by this type of injury (such as emotional lability), it is also required that each have sufficient temporal and emotional distance to allow perspective. As a result, volunteers who were in the early stages of recovery from TBI were not included in the study. Equally important was that participants (whose deficits included memory impairment) were able to recall events and subjective experiences over the course of their recovery.

It was essential that each was able not only to reflect upon, but also to articulate their experiences (Cochran & Claspell, 1987; Colaizzi, 1978). Impairment of executive functioning following TBI can interfere with a person's ability to plan and organize what one wants to do or say. If combined with impulsive behaviour and/or emotional lability, the attempt to describe personal experiences could be frustrating for the participant and non-productive for the researcher.

The final requirement was that each be at least 18 years of age and have experienced TBI at 16 years of age or older. The purpose of this requirement is to limit the study's focus to an adult perspective, to guarantee the participant's right to independent involvement in the study, and to eliminate confounding developmental issues associated with childhood TBI.

All of the factors listed above were reviewed through consultation with the referring source and in a screening interview. Neither severity of injury nor length of time post-injury were controlled variables. There was no screening for further demographic details such as pre-morbid personality traits, alcohol history, marital status, or responsibility for injury.

Screening Interviews

Candidates referred to the study were screened in an initial telephone contact to assure that each met the criteria described in the previous section. Each was asked his or her age, when he or she suffered the brain injury, how it happened and whether she or he believed that any recovery had taken place since that time. Each one was also asked what benefit they might receive from participating in the study. Those who entered the study expressed a desire to promote the study of traumatic brain injury.

The researcher then explained the purpose of the study, outlined what was being asked of the participant, and specified the need for two interviews lasting a total of three to five hours. Each was cautioned that reflecting upon past traumatic experiences can be upsetting. They were queried about whether they had any concerns about the process or the content of the interviews. The research question was briefly outlined so each understood that the nature of the study was to explore and understand their process of recovery from TBI. The researcher invited each person to ask questions regarding the study and to ensure that each was providing informed consent. The researcher then inquired whether the prospective volunteer was still interested in participating. Each was informed that the researcher required his or her signature on a consent form which was presented at the beginning of the first recovery interview (see Appendix B). A date and time was set to meet, and the participants were reminded that they could withdraw from the study at any time.

Interviews

Collection of data was done in an interactive and collaborative manner. The

research interview (Mishler, 1986) aims to elicit each person's story in depth and detail. The assumption is that the interview is a linguistic discourse and that "meaning is grounded in and constructed through the discourse" (p. 64). Information was gathered in a comprehensive, systematic and in-depth fashion (Patton, 1990). The trustworthiness of the accounts is supported by the rigor of the interviews, assuring free and open disclosure without distortion, deletions or additions, and by the commonalities. "Qualitative interviewing begins with the assumption that the perspective of others is meaningful, knowable and able to be made explicit" (Patton, 1990, p.278).

The goal of the interviews was to understand the nature of the participant's experience of recovery and its meaning to that person. The participant was apprised of the purpose of the interview and encouraged to participate actively in telling his or her story. The participants were told that the interviews would likely take a couple of hours but that we could stop at any time or take longer if they preferred.

A second interview with each participant permitted each one the opportunity to include events and memories that may have been forgotten in the first meeting. It was also designed so that the participant could review the narrative account drawn from the first interview and make any necessary corrections, additions or revisions. This step insured that the story was as accurate and true to that person's experience as possible.

The researcher took a facilitative posture throughout the interviews. Active listening, paraphrasing, summarizing, clarifying and other counselling interviewing skills were applied to empower each participant to tell his or her story fully and without undue influence. For example, "so you have some memories of your time in hospital but other

people have told you about things that happened as well. Sometimes its hard to sort out what you remember versus what you've been told". This type of response helped the participant describe a very confusing episode in early recovery. It also clarified the difference between personal experience and memories created by other people's descriptions. Simple reflection of feeling such as "you sound angry, even now, as you speak about incident" helped to clarify and expand upon the feelings the individual was experiencing in the past as well as in the present moment.

Each person was asked to provide a summary of his or her life prior to the injury. This was done to help identify significant life changes following TBI and explore both explicit and implicit losses. In other words, the researcher sought to understand what the person possessed and lost and also what goals had been anticipated but not realized as a result of the injury.

Once we shared some understanding of life pre-injury, the person was asked to speak about how their injury occurred. Clarifications were sought during this phase to determine how much was recalled by the participant and how much had to be provided by significant others. Finally, each person was asked to describe her or his experience of recovery from the time of the brain injury to the present.

According to Mishler (1986), "ambiguity and complexity are omnipresent in all situations and types of discourse" (p.45). This requires the interviewer recognize this and be skilled in attending, listening, clarifying, paraphrasing, and primary empathy to facilitate disclosure and respect the experience of the participants.

Narrative Accounts

"The most faithful model of life as it is lived is a story" (Cochran, 1986, p.14).

The story is drawn from the audio-tapes and the transcripts of the interviews with the participants. The researcher transcribed the interviews which provided further opportunity to be sensitive to participant and researcher responses, silences, voice tone and other units of communication. In constructing the narrative accounts, this process demands that the researcher return frequently to the original recordings and transcriptions to ensure an adequate interpretation. The person's description of his or her experiences of recovery is organized into chronological order which permits easier review of the story by the researcher and participant. His or her words are used in the narrative to retain, as much as possible, the voice and the perspective of the participant.

Participant review. The researcher returned to each participant for review of the narrative account. Each person was asked to read and/or listen to the narrative and make corrections or revisions and elaborate on what was said. This was done until the participant was able to go through the entire story without making any further changes to it. Once the participant determined that it represented an accurate account of his or her experience as described, each was asked to consider the themes or patterns which emerged in the analysis of the stories. The participant's opinion was sought regarding the accuracy and relevance of these patterns.

Independent review. A Ph.D. psychologist was asked to act as an independent reviewer to enhance the credibility of the study. He was asked to read the transcripts of the audiotaped interviews and determine whether the interviewer created any bias in the

participant responses. He was also offered the audio-taped interviews. He was then asked to read the narrative accounts and assess whether they represented an accurate portrayal of the participant's verbalized story. The questions posed to the independent reviewer are located in Appendix C.

Comparative pattern analysis. The goal was to identify whether there existed patterns of experience which were common to many or all of the participants. The intent was to identify experiences which aligned in a meaningful way. Guba (1978) stated that too many items of data which are unassignable or overlapping highlight a faulty category-classification system. He claimed that the set of categories should be plausible, inclusive of all data, reproducible by an objective judge and credible to the participant who provided the information on which it is based. Patton (1990) warns that the researcher's attempt to uncover patterns, themes and categories leaves open the risk that the investigator will determine that something is meaningless when it is meaningful or that it has significance when it does not. The researcher addressed these concerns by providing concrete examples from each narrative to support the validity of a proposed theme or category. Patton (1990) also suggested that creativity is an important component of qualitative study. It strengthens the analysis, interpretation and reporting when combined with critical thinking, a blending of science and art.

The following seven chapters contain the narrative accounts of the study participants. A sample transcript is provided in Appendix D. The narrative accounts are intended to reflect as accurately as possible, the story of each person. For that reason, their words are used as much as possible. Thus, each account differs somewhat in

vocabulary and in tone. Following each narrative is a commentary in the words of the researcher which represents the researcher's understanding of the story in general and of significant events or experiences in particular. Table 1 lists the seven participants, their gender, approximate age, length of time since injury, employment status at the time of the injury and employment status at the time of the interviews.

Table 1

Descriptive summary of the participants

NAME	SEX	AGE	TIME SINCE INJURY	EMPLOYMENT STATUS AT TIME OF INJURY	EMPLOYMENT STATUS AT TIME OF INTERVIEW
S.R.	M	late 20s	9 yrs	Student	Works with street kids
J.G.	M	early 50s	10 yrs	Respiratory Therapist	Hospital volunteer
G.S.	M	mid 40s	7 yrs	Refinery worker & horse trainer	Part-time student
S.P.	F	late 20s	6 yrs	Unemployed	Unemployed
I.G.	F	early 50s	3 yrs	Social services administrator	Unemployed
R.S.	M	early 30s	11 yrs	Apprentice	Apprentice
S.C.	F	early 40s	4 yrs	Daycare operator	Daycare operator

Perspective of the researcher

As a clinician, part of my role is to motivate clients to accept and participate in rehabilitation activities. This is important, particularly early on when self-awareness is limited. However, I often find myself empathizing with their complaints of being overwhelmed by bureaucracy, impersonalization and interventions which run contrary to

their needs but which meet someone else's agenda. Mishler's (1986) model for research interviewing recognizes that the researcher enters the process with values and beliefs and systematically addresses the ways to minimize bias. As a result, this study afforded the opportunity to gain a new conceptualization of how and why people with TBI may be encountering these difficulties.

CHAPTER IV

CASE STUDY ONE: S.R.

S. grew up in a close family which included his mother, father and younger brother. His parents were caring and supportive. He was a role model to his brother. He knew himself to be intelligent, funny, well-liked and self-confident. He was at the top of his class at school without effort. He was often told that he was extremely bright and he grew up believing he could be whatever he wanted to be. Ever since he was five years old he wanted to be a lawyer. As he progressed through high school, he anticipated attendance at university leading to a successful career in law. He expected a high salary which he would use to support a beautiful wife and children. He felt optimistic and confident about his future. His first year at UBC, 1985-1986, was not an academic success however. He didn't apply himself and it showed in his grades. He decided to take some upgrading courses in the summer and worked diligently to redeem himself. He would attend the University of Victoria in the fall of 1986.

On August 13, 1986 S. came home from work, got on his bicycle and went for a ride. Shortly thereafter, he was struck by a truck. The police found his younger brother at home and brought him to identify S. He had suffered knee and back injuries and a traumatic brain injury. His parents, on the advise of their lawyer, rejected a \$20,000 settlement offer from the insurance company. S. remained in a coma for 10 days.

When S. regained consciousness he was in considerable pain, he had no equilibrium, and he could not walk. One side of his head was numb and his eyes were black. He called anyone, including his mother, the worst possible names in the book. S.

has no recollection of the time in hospital but he filled in the gap with a variety of stories, some remarkably far-fetched. He believed he was totally fine.

When people came to visit, he was able to talk to them appropriately, indicating he knew who the person was. When his brother walked in and S. called him by his name, it was a big deal for the family. It was the first time he had addressed anyone by name. Within a minute his father had to restrain S. from trying to kill his brother. He went through dramatic emotional swings. At one point the medical staff forced him to wear a straitjacket because he kept wandering away.

S. was released from hospital August 28, 1986. His doctors recommended transfer to another hospital for therapy. His parents didn't think this was the best idea. The alternative suggestion was that his parents take him home and hired a babysitter for a year. S. was not going to accept an idea like that one. At times S. was in agony and he would admit to pain from his knee or his back but not from his head. He had to go to doctors' offices, so many doctors' offices. They ran tests like asking him to count backwards from 100 by threes. He would scream and swear at them, angry and insulted at the tasks they presented. They should just get out of his way. If they wanted him to do something as simple and as remedial as those tasks then they could all go to hell.

Everyone told S. that he couldn't return to university. They said it would be too stressful and he wasn't capable. He argued about it with his doctors, his family and his friends. He knew his shortcoming would never be his brain. He knew he was a funny guy who was very smart and who could do whatever he wanted. If he wanted to become a lawyer, he could easily become a lawyer. The family agreed to meet with their

physician and let him decide. S. recalls being asked to perform a simple task, the kind of thing he could still do very well. The doctor commented that S. could perform this task better than he could. He was leaving the decision up to the family. They returned home and S. told them they had another thing coming if they expected him to stay. They drove him to UVic and dropped him off. He was in residence on September 6, 1986.

When he first arrived he couldn't stand up, his equilibrium was shot, his knee was killing him and he could barely hold a conversation. Even so, if someone had asked him to play football or get drunk, he'd have been there. During a visit home, he told his mother he was going to ride a stationary bike. His mother told him he couldn't because of his knee but he argued back and forth with her. Then he told her he could run up and down the stairs fifty times. In his house the stairs ascended to a small landing and a large glass window. One had to turn to ascend the rest of the staircase. He argued over this with his mother until his friend, fed up with the bickering, told him to go ahead and do it. At that point he told her he didn't have to prove anything and he wasn't going to do it. It seemed there was always someone telling him that he couldn't do certain things because he had been in an accident. He would tell them where to go and how fast to get there. He'd tell them he was going to play football or box. They would tell him he couldn't. He kept pushing. Everyone was saying no, no, no and he was saying yes, yes, yes. They all treated him with kid gloves.

S. attended Camosun College since his accident had prevented him from completing the summer upgrading courses. He was given permission to maintain his residence status at UVic, a few blocks from the college. On the day he went to register

he had \$500 cash for his tuition. On the way there he stopped at a stereo store to purchase a compact disk. By the time he left he had four CDs and a CD player. He returned to his dorm and was listening to his new sound system when he suddenly realized that he had blown all the money he needed to enrol. He was devastated, he couldn't believe what he had done. What had he been thinking? Where was his head? He had to call his parents and tell him what had happened. They gave him more money, told him to try not to do it again and not to worry.

Probably the most disturbing event after his injury occurred on October 17, 1986, two months after his accident. He was visiting a friend's place in residence. While his friend was out of the room, S.'s best friend grabbed a couple of pieces of pizza from a box that looked like it had been there for a month and a half. He threw them in the toaster oven. S. demanded to know why he was taking them without their friend's permission. He was stealing this pizza. S. was so upset about this that he was on the verge of physically fighting his best friend. Their friend returned and said it was OK to eat the pizza. At that point it hit him, "Oh my God, I'm not the same person, I've changed!". He ran back to his room, crying the whole way. He had no control, over his own mind or over his own actions.

His obsession became how to change back. He began questioning his friends incessantly to determine how he was different. He discovered he had a temper that was very short-fused. He didn't have any social graces and would be as likely to tell an incredibly vulgar joke in front of his grandma as anyone else. His friends were constantly apologizing for him. These traits were not typical of the old S. He'd lost

himself and the only way he could figure to get that back was to analyze himself, the way he acted, and the way he thought. Experiences were assessed and categorized as belonging to either pre-accident S. or post-accident S. If he attributed it to post-accident S., he tried to correct it right away.

S. discovered the value of structure in his life and he clung to it obsessively. Each night he wrote down what he had to do the following day. The list started with having a shower and eating breakfast. The lists structured his day down to the second. For example he might be with friends at 4:00 but he had to leave at 4:45 to go home and iron until 5:45. Then he vacuumed from 5:45 to 7:00. If it was on his list, he just left in the middle of whatever activity he'd been engaged in. It was the only way he felt he could get things accomplished. If they told him to relax, he would get angry. It was like they were dissuading him from getting anything accomplished, from doing the things he needed to do. In one instance he told a girlfriend that they would leave the house the next morning at 8:36. He sat at the door with his shoes on and it drove him crazy that she was late and they left at 8:39. He was so upset that the rest of the day was shot. If he was late for an appointment, that was the end of his day, he couldn't get back on track. Having a structure and following it completely seemed like the only way to regain some control in his life.

After completing two of his five courses at Camosun College, S. returned to UBC the following September. He found it difficult to stay on task. He couldn't decide when he wanted to study and when he didn't. A computer was purchased for him. It was programmed with a dayplanner to include the list of things to do each morning and

afternoon. It didn't work. He saw a neuropsychologist at the beginning of each week. They set up a plan for that week and reviewed goals of the previous week. Still, none of it got done. The plan was revised to make him more accountable, more regularly. At first he phoned in everyday. Then he got on the computers at the university and used the modem to make daily contact with her office. It didn't matter. The strategies worked like a charm as a novelty. He got little tastes of good solid work, enough to make him believe he could do it. Then the novelty wore off and he was back to square one. The treatment plan became too intrusive when it was suggested that someone live with him. He flatly refused. Each term was the same. He received good marks on the papers he submitted but since they were late the grade was reduced. He failed courses because he didn't hand in the term paper or he hadn't opened the textbook. So he got 60% on his transcript, just like his first year.

During the summer he tried to manage a student painters business. It cost him thousands of dollars for start-up. He needed to begin his day at 6:00 a.m., work long hours day and night banging on doors selling paint jobs. It required an immense amount of self-motivation. He couldn't do it and he lost thousands of dollars as a result.

September 1988 found S. continuing studies at UBC. The story was the same. That summer he invested \$5,000 in frozen food, dry ice and truck rental for door-to-door sales. Success was dependent on how much one worked. A friend gave him a clipboard, coloured pens and a sheet of paper with 100 houses on it so he could categorize each one he went to and meet his daily quota. Sometimes this worked and he sold a lot. More often he drove home and took a nap. Again he lost thousands of dollars.

Over time, S.'s friends became annoyed with his strict adherence to his daily time line. One friend challenged his priorities, arguing that he was making tasks such as ironing more important than his friends. He argued with her but she made her point. Gradually he learned to become more task oriented and less time focused when it came to motivating himself. He had to balance his priorities.

S. persevered at UBC and finished his B.A. in Psychology in 1990. By then he was no longer interested in becoming a lawyer. Regardless, he wrote the LSAT. He scored in the 90th percentile but his grade point average was too low. He was not accepted into law school. He decided to do a qualifying year so he could then apply to a graduate program in counselling psychology.

With his trial approaching S. was told that people close to him would be asked to talk to his lawyer about the accident. S.'s best friend hadn't talked about the accident for years. When S. confronted him on the need to bring things into the open, his friend broke down and cried. S. explained to his brother that he would be asked about what it had been like for him, how S. had changed, and how he felt about it. His brother shrugged it off but S. insisted they talk about it. His brother told him that the hardest part about the accident for him was that he lost his older brother. It was really hard to hear how much people he cared about had been hurt by his accident. It was difficult to confront the changes that deeply affected them all. It was a very emotional time for S.

The trial took nine days in the middle of December exams in 1990 so S. was forced to give up the semester. In court the argument made was that S. was a different person as a result of the accident. S. was less of a person. S. was not the person he

used to be or could have been. It was a sad and disturbing picture. They presented a totally negative picture which, they reasoned, would not have happened were it not for the accident. The analogy used was that if you took a computer with lots and lots of software but without the operating system, you couldn't access the software. Here was this really bright guy who can no longer use that brilliance because he doesn't have the motivation, he doesn't have the drive to do the things that are necessary.

S. knew intellectually what his family and friends would say but even so, he was not emotionally prepared for it. They had been so positive, treating him as if nothing had happened, not like he was screwed up. His family rarely spoke of negative things. He never talked with either of his parents about how they felt. In court S. listened to the people he cared about speak of his accident, the resultant struggle and of their pain and loss. It was very, very hard for S. to hear.

The reports presented at his trial suggested a predictable vocational pattern. They described a person with the verbal skills to walk into an interview for a managerial position and get the job. The employer would quickly come to realize he couldn't do the work and he would be fired. Then he would then take a job more suited to his skill, brainless, repetitive, assembly line work which would bore him so he would seek out another managerial position, get fired, return to menial work and that would be the cycle. S. was afraid of this predicted pattern. He was afraid it was correct and that it spoke of a future to which he was doomed.

The court awarded S. approximately one million dollars. The size of the settlement felt like a terrible burden. The message seemed to be that he couldn't hold a

job so the money would have to last for the rest of his life. If he ran out at 60, he didn't eat for the next 20 years.

On the bright side, S. suddenly realized he wasn't fighting any more. Since he wasn't at university he was no longer struggling to complete his to-do list everyday. It was quite a change to be experiencing a relaxing life free of the pressures he'd been under for four and a half years.

Part of the award was a three month vocational counselling program. A job placement was arranged for S. They told the employer that he had suffered a brain injury and what the employer could expect from him. They explained that they were assisting him in holding a job. One of the things they also told his employer, which he wasn't happy about, was how much money he'd received in his settlement. It was a volunteer position that eventually turned into a full-time job. After S. had been there a couple of months, a co-worker told him he was different because of his money, that he could just forget about the job anytime. He was absolutely livid that somebody could make an implicit suggestion that he wasn't working very hard.

Some of his experiences with the vocational program served to confirm his fears about the predicted vocational pattern. He was labelled "brain-injured" before he started the job, all the employers knew this about him and when he wasn't successful at a job, he had lots of support and a good excuse. He fulfilled their expectations many times.

One job, in particular, had a profound impact on S. This was a job he had found independently and it was a crucial experience because he was there on his own merit, without excuses. His employer did not know of his brain injury. It was a pretty good

job in some respects, but not one he particularly loved. Still, he was being paid a lot of money and it was in his area. It was great with the exception of that fact that he was late almost every day. One day he was outright dragged into the office and told, "S. give me your keys and get out of here". He was stunned. "Give me your key, get out, you're fired, like get outta here".

After getting fired, he spent 18 months fooling around and playing golf. That convinced him he was in no position to retire. He had no desire to be idle. He had lots of things that he wanted to do, lots of people he wanted to help. Being fired forced him to look at himself for the changes necessary to be successful instead of the excuses relied on in the vocational program. He realized that when there's too much support, he would buy into it and become dependent. It wasn't just a place to go and collect a pay cheque. He needed to be in control. Work was crucial to his self-esteem.

He took a job at a dating service selling packages. It was a ridiculous job but he now realized the significance of having work. He had been shaken by having the carpet yanked from under him. He was never late for that job.

S. wasn't ready to give up the academic fight. Two years after his trial he returned to university, this time pursuing his focus of interest, counselling psychology. He had a B.A. in psychology and he had done a lot of work in the field. He registered for two courses and almost immediately realized it wasn't the place for him. He loved the whole learning process but he hated having to hand in anything, he hated knowing he wasn't doing the work and connecting it to having this "problem". He knew he had to get out and not come back. It was a painful realization that the ability wasn't there, that

he would not be able to pursue graduate degrees. A professor in career counselling pointed out that if you have a career path but you can't accomplish it, you have to face it and dream a new dream.

While the first time he left UBC had been frustrating and painful, the second time was different. Initially he had been locked into the struggle to succeed and prove everyone wrong or, if necessary, to fail so that he could be compensated for the loss. By the second time he had tried some jobs and realized he had options. He believed a new plan could materialize without an M.A. or PhD. There was less desperation the second time. The drive had been broken, the obsession was over. He experienced a freedom that was not present before. He started to believe he could find a new dream.

Eventually S. attained a job working with street kids. He begins work at one o'clock in afternoon and he's never been late. He has learned about work habits, what is acceptable and what isn't. Recently, he finished the probation period for the job. He's been at the job now for ten months and doesn't know at what point he'll feel like he's truly there to stay. He doesn't see himself leaving and he doesn't see anyone asking him to leave. This is what he loves to do and he can't imagine ever giving it up. This is his career. All along, that was the most important struggle. If he was laid off, questions regarding the prognosis would return and he'd feel like he was back at square one. The balance is definitely fragile.

In retrospect he decided that his co-worker words of years ago were bang on. He figured out just how difficult it was to hold a job knowing he had enough money to retire at any time. He views the money as a burden. He wonders if it would have been

necessary to get fired until he got it right if he didn't have the money. He wonders if the prognosis created the problem and is inclined to believe it did. Without the money and without the excuses, he would have had more drive and motivation because he would have had to earn his way. Instead, he had money to burn while his self-esteem took a battering over the long, arduous process.

He admits that he's not always so nonchalant about the fact that he has a B.A. and that's where it stops. It's hard not to feel like he lost something there. He can get tied into the sadness of not having a Masters degree or PhD. He can look at his ability to get a good score on an exam and know that without the accident he could have the high grades to go with it. But it doesn't help to get caught up in the grief and the pain is no longer as intense thanks to his current work. When he was struggling to identify who he was and what career he was going to hold, the loss of opportunity in education felt much greater. He likens it to relationships. You're always bummed out about the loss of your last relationship until you meet somebody else. He's found a new path and that helps him live with the ones that were lost.

Coping with the emotional burden was a lonely struggle. He can't even imagine where he'd be without the kind of support network of family and friends that he had. Wonderful, non-judgmental friends stuck through it all and with their help he learned to be more flexible without sacrificing accomplishments. When he reflects on many of his behaviours (such as his rigid adherence to structure, interactions with his friends and experiences at the various jobs along the way) it leaves him feeling embarrassed. Perhaps hardest of all was the loss of ability to rely on his own judgement.

Professionals identified problems and barriers and offered strategies and techniques. He never talked about what he was going through. He doesn't remember ever being asked what it was like to keep struggling to become a lawyer. He doesn't recall anyone asking about the impact of the injury on his life. He wonders if he was just good at artfully dodging such questions. He realizes he was afraid of expressing just how hard it was. He didn't understand the motivations which directed his emotional energy straight back into his fight to meet his original goal. No one helped him explore how to make it easier. Medical, legal and rehabilitation professionals made him do things he couldn't do for five years to prove he couldn't do it. It was not worth it. He emerged with a degree and financial security but he'd trade all the money back if he could. It was a waste of time, energy and self-esteem.

S. is astonished at the extent of the negativity he heard over the years. The focus was on what he couldn't do, not on the abilities that could help him find a new way. Even the brain injury groups he attended seemed to dwell on the negatives. Victims only need apply. A person who sees himself as self-sufficient and capable of getting through the hardships doesn't go there. The negative stuff just further entrenched him the fight for the old dream. It took a long time for his dislike of negativity to permit him to do some reality checking. He wonders what it would have been like if someone had said, S. you'd be great at this, why don't you try it. The biggest things that shook him out his stance, out of his stubborn quest for his original goals, were positive gains in other directions.

He attributes much of his emotional struggle to his previously high self-esteem. If

he hadn't liked himself as much, perhaps he wouldn't have tried so hard to return to who he was. But, rightly or wrongly he believed himself to be the smartest guy alive and the greatest person you'd ever want to meet. The fact that he was a teenager inherently meant that he was way too cocky anyway. But these factors made it difficult to accept the fact that he'd changed. He believes his self-esteem is different now, because he has matured and because of the changes from TBI. He no longer has blind self-confidence but he feels pretty good about himself. There have been a lot of changes in the past ten years. His self-esteem was definitely damaged by the negativity, by his enduring battle to dispel limitations set by others. As soon as someone suggested something he couldn't do, it could be anything at all, he'd go out and do it. As a result, he can't distinguish between failures which stem from his injury and the ones for which he never had the interest or the ability in the first place. It seems obvious to him that when he wanted to test his limits, he needed people to say, go ahead, give it a whirl and tell us how you do. He needed to find his own answers.

Today S. is happy in his career, he's in a wonderful relationship, he remains close to his family, he lives in his Kitsilano home, and he enjoys his friends. He has found a career that doesn't clash with his difficulty getting out of bed in the morning and if he doesn't get around to certain chores he hires someone else to do them. He's enjoying what he's good at and managing the things he's not good at. Many of his accomplishments are what he expected when he was younger and looking to the future. The road that led to those accomplishments is nothing he could have anticipated.

COMMENTARY

When S.'s story began, he was confronted with enormous challenges. He didn't know what had happened to him. He was in a great deal of pain due to the injuries to his knee, his back and his head. He had gaps in his memory, time and experiences he could not account for. His recognition of and reaction to people he loved swung from one extreme to the other. For example, it was his brother whom he first called by name but then wanted to kill. His behaviour was so erratic that he was restrained with a straitjacket.

Everything S. knew about himself was contradicted by others. He knew himself to be independent and capable, yet doctors recommended he have a babysitter. He knew he was intelligent but they made him take simple tests and told him not to return to university. Worst of all, they told him he could not become a lawyer. It didn't make any sense to S.

He could not accept limitations imposed by others. He had to carry out his plan to attend the University of Victoria. Whenever people challenged his ability to do something, he would take on that challenge. If they wanted him to lift a house, he would lift a house. He would prove them all wrong and become a lawyer as planned.

As life carried on, some of the changes he had undergone became apparent to him. He determined to regain control by using whatever strategies worked. He made lists to plan accomplishments for each day. It was essential to him that he meet these goals. If not, he felt devastated. The pressure he felt from others to abandon this practice was perceived as their lack of support for him and for his goals.

While he was attempting to acknowledge problems and find ways to overcome them, S. found himself in a new environment which focused exclusively on deficits. During his rehab he was constantly reminded of his limitations. He needed to know his abilities. They seemed committed to pointing out his disabilities. As he navigated through these new waters, S. was also exposed to changes in his interactions with familiar people in his life. He was the guy who could do anything as far as his younger brother was concerned. That was no longer the case. His friends were apologizing to others for his behaviour and they became annoyed when his daily structure minimized their role and prevented spontaneity. His parents gave him money and did not demand accountability as they normally would and as they did of his brother. Everyone was supportive but in a different way than before his accident.

For a considerable length of time, the world as S. knew it was not working. It was as if someone had changed the rules and forgot to tell him. As he lived his life post-injury, certain incidents caused S. to reevaluate himself and his abilities. They were emotionally powerful events that challenged his assumptions, his expectations and his own self-awareness.

When S. discovered that he had unwittingly spent his tuition money on a CD player, he was devastated. It was not like him to be so irresponsible and absent-minded. It was embarrassing to have to call his parents and ask for more money. This behaviour was out of character for S. He hadn't acted in a way he could have anticipated and not being able to predict his own behaviour was terribly unsettling.

S. was on the verge of a physical fight with his best friend over a rotting piece of

pizza when it suddenly struck him that he had never treated his friend this way. He was not physically aggressive by nature and it was unthinkable that he be that way with his best friend. S. was overwhelmed by the realization that he was different, that he had changed as a result of his injury. Once past the initial, devastating shock, he faced this new reality by obsessing over how to get back to being his old self. He started grilling his friends about the specifics of his changed behaviour. He wanted to be as he was before his accident but he needed them to tell him who he was.

Despite his efforts and rehabilitation-based assistance, the end of each academic year produced a 60% grade point average. S. knew he needed to do better if he were to compete for entry into law school. Each autumn he returned convinced he could do what was necessary to get high marks that term. Each time he was sure it would be different. Each time, it was not. Although he continued to hold on to it, the dream was fading.

The world of work was no easier. His summer job ended up costing him thousands of dollars in investments and lost wages. He couldn't find the energy or the strategies to succeed. Still, he was so determined to prove he could do it, he tried a second time, the following summer, with the same results.

S.'s decision to confront his brother and his best friend regarding changes in him since his injury led to powerful, emotional reactions. S. hadn't given much thought to what they had been through and it was tough to listen to what they had to say. Separately they told him that he was different and it hurt them to have lost the S. they used to know. The power of the statements was profound as was S.'s realization of how much pain they too had suffered. These sentiments were expressed over and over at his

trial by the people who knew him and were close to him. Everyone was grieving the loss of the old S. and he was struck by their pain and their shared story of change.

Giving up his academic semester because of the trial was significant for S. Although not by choice, he was finally out of UBC. "If it hadn't been for my trial I feel like I could quite conceivably still be doing qualifying years, five years later". He was trapped by his own determination to prove he could do it and it was only under duress that he broke free of it.

In court, experts predicted that his future employment would be erratic and unsuccessful. He was awarded a one million dollar settlement which seemed in line with the negative prognosis. S. would need this money because he would not be able to work. Pre-accident S., the man who would be a successful lawyer, was gone according to the experts. Worse still, the people who assessed him could not foresee any job he would be able to maintain consistently.

S. needed his own answers. He returned to UBC to pursue qualifying courses for a graduate degree in counselling psychology. It was then that he concluded that he could not succeed in academia. He had given up his dream to be a lawyer and at this point his dream of attaining graduate degrees ended.

Other pivotal moments seemed to lead to new perspectives or new values for S. For example, when he was challenged by a friend that his time-oriented day plan interfered with the priorities in his life, S. initially disagreed. She suggested that he was acting as if ironing was more important than his friends and he knew this was a ridiculous idea. Upon reflection however, he started to understand what she meant. He

revised his approach so that he could still accomplish tasks each day but in a more flexible way. He could set priorities without sacrificing necessities. He discovered he could be less rigid, equally constructive, and experience less stress in the process.

S.'s experience of getting fired was particularly profound because he thought he had eliminated the role of the brain injury and he failed nonetheless. A long period of time without work concluded when he realized that he needed work, not for the financial remuneration, but for his own self-esteem. These new values were put into practice at his dating service job and subsequent positions.

When S. left UBC the second time he was able to say good-bye to his career as a student. He asked his own questions and received his own answers. He had also learned that he could be vocationally satisfied without graduate training. There was a sense of closure, not devoid of regret, when he took leave of academia for good.

When he secured a job working with street kids, S. knew that he was doing what he wanted to do. The work was meaningful for him, he was contributing and he was enjoying himself. Completing the probation period allowed him a cautious sense of security regarding his career. This was the light at the end of the tunnel that indicated that perhaps his future was not as bleak as others predicted.

By the end of his story, S.'s self-predictability had strengthened and his behaviour met with his expectations of himself. Feedback from others was congruent with his perception of himself. The friction that was prevalent in the beginning had subsided. His successful completion of his probation period at work confirmed agreement between himself and his employer regarding the requirements of the job and his performance.

Relationships in his life were central, supportive, and positive. He remained close to his parents and brother, had a strong network of friends, and enjoyed a wonderful, intimate relationship. He liked the things we was doing both socially and in his career. He felt satisfied with his life. He had matured and emerged from his experiences with a new kind of self-confidence and optimism. He liked himself and was surrounded by others who liked him too. Importantly, this state of being felt relatively secure and predictable. He had his home, his family, his friends, his relationship, his job, and his judgment which said, happily, that this was where he was going to be for the foreseeable future.

CHAPTER V

CASE STUDY TWO: J.G.

J. was a respiratory therapist at a large urban hospital. He worked twelve hour shifts and on his days off he drove to Portland and worked in a hospital there. He drove back in time for one day's rest before his next local shift. This lifestyle allowed him to earn extra money and to become familiar with both the Canadian and American medical systems. J. knew there was potential for advancement in his career. He planned to take advanced courses giving him the opportunity to become the respiratory head in the emergency ward or the intensive care unit. The promotion offered better working hours (eight-hour shifts instead of twelve) and a salary increase.

J. was married with one son. He was the head of the household and generally the one to make the decisions in the family. J. did not see a lot of his family. When he returned home from the night shift, his wife had gone to work and his son was at school. He slept all day and by the time they returned home, he was due back at the hospital. J. was in good physical condition. He jogged to the hospital and back each day. When he wasn't in Portland he attended martial arts training.

In March 1985, J. was 42 years old. He drove to his son's school to pick him up. On the way he hit a patch of black ice. His car skidded out of control and hit a telephone pole. The vehicle was bent into an L-shape. It took 45 minutes for rescue workers to cut through the vehicle to get him out. He was rushed to the same hospital where he worked. His face was so badly disfigured that no one recognized him. Even a co-worker who boarded in J.'s house didn't realize who he was. He was listed as John Doe.

J. sustained a traumatic brain injury and two broken legs. Neurosurgery was required and twice the doctors had to perform a craniotomy to relieve the cranial pressure caused by the swelling of his brain. J. was unconscious for 72 hours. When he emerged from the coma, he was confused and disoriented. His wife told him later that he kept struggling and demanded to be allowed to get up. At one point, he pulled out his catheter, causing a lot of bleeding. After that he had to be restrained.

J.'s co-worker brought him a tape recorder so that J. could listen to music. His friend knew how much he loved music and he brought in J.'s favourite audiotapes. Most of the time he was really confused but sometimes he listened to the music and was calmed by it. J. was transferred to a rehabilitation hospital for a month and then, in May 1985, to another rehabilitation facility. He was in a wheelchair and the medical staff began work on strengthening his legs. It was terribly painful. What was even more frustrating was the loss of his ability to verbalize his thoughts. He understood what was said to him but nothing he said made any sense to them. People kept asking him to repeat himself over and over again. He couldn't understand why they didn't know what he was saying. He was confused so he just did what he was told and hoped it would work out. When he felt low or frustrated, he would calm himself with his music.

He was assigned to the third floor which meant he was woken up for breakfast and bathing and had assigned seating and meals. He worked hard at the daily physical therapy on his legs. He really wanted to get out of the wheelchair. He experienced a lot of discomfort on his left side and so he always lay on his right side. He didn't know why it hurt but he didn't complain. After several months one of the staff asked him why

he favoured one side. He told her it was sore and she explained that the screw that was put in his leg was too big because they didn't have the right size in the emergency ward. The screw was removed and J.'s physical relief was considerable.

Communicating was extremely frustrating for J. His wife told him that what he said made no sense. His son explained that his speech was like a telegram, all shortcuts. The speech therapist told him to slow down and think about his answer before he responded. She said he talked too quickly and since English was not his first language, it was hard to understand him. He tried to do as he was told and kept repeating himself whenever someone said pardon. He still felt confused but he followed their directions. He had to trust them to know what was best for him.

On Fridays J. was allowed to go home for the weekend. Although his wife didn't pick him up until 5:00 in the evening, he got up and went for breakfast and then went straight to the lobby to wait for her. He was called for his rehab program which went until lunch time. He ate lunch and then returned to the lobby. Again he was taken for more physical rehabilitation on his legs in the afternoon. As soon as he was finished he hurried back to the lobby to wait. He was glad to get home. On Sunday mornings he knew he had to return. He went to church with his family, came home at noon and waited in his chair, counting the hours, minutes, and seconds until she drove him back to the rehabilitation centre.

One Sunday afternoon, J. was confronted by his wife and son. He explained that he didn't like returning to the centre. They told him he was crazy. They pointed out that he was not a prisoner there, that it was for his own benefit. Their words rang true,

particularly since he'd been reading a book on head injury which said the stages of mental recovery took a long time. J. returned to the rehabilitation centre and to his roommate there. He was a likeable man who had suffered a spinal cord injury. He needed a lot of assistance from staff. His roommate went to bed at 10 p.m. and then called for nurses every five or ten minutes. J. was mad about this but then he realized "gee whiz, I can walk around, I'm luckier than this guy. He never can".

After a few months J. was transferred to the second floor, which meant he was getting better. It meant less structure and more independence. He could get up and go to the cafeteria on his own. He could select his food and sit where he wanted. In physiotherapy he was making progress. He had been using a walker for an hour per day for strengthening exercises. Then he began alternating between his wheelchair and a cane. His goal was to walk without any aids.

By the fall of 1985, J. was going from his wheelchair to walking without the use of a cane. He decided that more he used the cane, the harder it was to achieve independence. He was also making progress in his group therapy. He began making presentations to the group, describing his daily activities and plans. Although it was still difficult, he was working hard to be understood by the others.

At that time, J. was asked if he would like to learn to drive again. He said sure, he'd take lessons so he started right from the beginning. He found it very difficult. It was frightening to be driving again. He gripped hard onto the steering wheel and put all his energy into concentrating completely on the task. The music which he normally loved was a distraction he couldn't tolerate when driving. There was so much to pay

attention to. By the end of each two hour session he was exhausted.

In February 1986, J. completed the rehab program and returned home. He was happy to be home but after the structure of the centre, he didn't know what to do. He didn't seem to have any motivation and he felt depressed. When he was on his own, he felt lost and stuck. J. just wanted to go back to work. He could see the hospital from his window. It was so frustrating that he wasn't permitted to work. He was determined that he would return. In the meantime, he felt discouraged, like he had taken a big step backwards.

J. was directed to a rehabilitation service which provided a worker two or three times per week. She would come to the house at 2 o'clock in the afternoon. J. stayed up until 2 or 3 a.m. watching television and then slept until she arrived. He looked forward to her arrival so they could do something. She helped J. work on his speech and his daily living skills. He did household chores such as cooking and shopping. It was like learning everything from square one again. To manage his memory problems, he was instructed to write down everything he needed to remember.

J. was asked about his interests and he listed music, photography, and self-defense. He was encouraged to pursue these hobbies. He started listening to different kinds of music. He discovered classical and jazz. He was greatly impressed by the genius of some of the great composers. He signed up for a course in photography. Instead of just snapping shots, he began to learn the technical side of cameras. He found that 36 shots on a roll might produce only three or four worth keeping.

J.'s rehab worker was well-qualified in martial arts and encouraged his re-entry.

J. went back to his dojo three times per week. His son decided to join him. He had to start back at the beginning level. He didn't mind because he knew what he was doing, he felt confident, and was pleased to be back. His legs were strengthening with the exercise and people were surprised at his knowledge for a beginner. The martial arts required discipline and this appealed to him.

J. spent some of his time at home reviewing his medical textbooks to gain a better understanding of his injury. The more he read, the more he realized that he could have died or been much more severely disabled. The books confirmed that recovery was slow.

The rehabilitation service met J.'s request to return to his hospital by arranging monitored volunteer work. He helped elderly patients by talking to them and joining them on field trips. This activity gave J. immense pleasure because he was familiar with the surroundings, he understood the needs of the patients, and now he could take the time to talk with them and contribute to their quality of life. Some of the things they said made him laugh and laugh. He was always careful not to laugh in front of them so they wouldn't be offended.

J. had some difficulty dealing with the rehab worker. She referred to him as brain damaged which he did not like. He explained to her that he understood the truth of it but preferred terms such as head injury or mental deficits. She didn't seem to take into consideration his education or background in medicine. He didn't think she was very tactful or respectful. He and his wife decided to switch rehab services, hoping to find something more professional. They consulted with their insurance company and were

directed to community-based rehabilitation service in the city. J. attended sessions twice per week, focusing on cognitive remediation and personal counselling. There he saw other people with injuries that were worse than his. He encountered people younger than him who were still in wheelchairs. He was able to travel by bus and even drive to his appointments. Others relied on the Handidart. He began to feel very lucky. He was encouraged to expand his volunteer work at the hospitals. His experiences and his reading led him to the realization that he would not return to his previous employment. The decisions he used to make were life and death and he couldn't imagine making them any more.

J. joined a social centre for people with brain injuries. He spent four hours a couple of times per week going on field trips and participating in social events. He saw people he knew from his first rehabilitation service and realized he had progressed well by comparison. His son saw some of the people with severe communication and mobility problems and announced to his father that he was the most normal one there. One day when J. was driving with his son and nephew he spotted friend from the centre and stopped to say hello. The man walked with a cane and did not remember J. at first. J.'s nephew later commented on how lucky his uncle was compared to some of these people. He said that the fact that his uncle recognized people, was driving, and had returned to self-defense class was proof of this. J. did feel he was very fortunate.

J. joined the Knights of Columbus and the Lions International. Both his father and father-in-law had been members. He had considered joining in the past but he didn't know who to approach. While volunteering at the hospital, he met a group of them

doing charity work and they offered to sponsor him. He became more involved with the church and community than he had ever had time for prior to his injury. He joined the church choir because he loved the music. His spirituality didn't change. Rather, he found he had the time to get more actively involved. At the John Simpson Centre, he met people who found a religion after their injury and who were really, really serious about it. By contrast, J. was always a religious person but his role in church activities increased. He also found a comfort zone in that commitment. He felt pressure from others to be involved in the executive committee of the Lions Club but turned down the offer in favour of being a member in good standing. He could have done the work but he just didn't want the headaches. Every group has its politics and he was happy to steer clear of the traps.

J. continued with the rehab service for two or three years and as he improved, his sessions reduced to weekly, bi-weekly, and eventually monthly. He became busier with his own activities and less immersed in rehab. In the early 1990's he attended a rehab program offered through one of the hospitals. He went to get help with his speech production but was admitted into a three month research study. He was instructed to use an electronic diary which he found efficient and reliable for keeping track of information and commitments. In the program the participants worked on a lot of cognitive retraining exercises. A lot of them complained about it but J. believed it was all for his own good. He also decided you can't rush it. If it is premature you can't make people appreciate it. They get there when they are ready. It depended on the type of injury and the person. Each one is different. Completion of the study marked the end of J.'s involvement in

formal rehabilitation.

J. identifies both challenges and rewards in his life following TBI. He knows that he lost a lot of power, authority and independence. He also knows that he is not the same person and that this change has been hard on his wife and son. The roles between he and his wife have been reversed. Now she makes most of the decisions and does the planning. She takes charge of the family's finances including paying the bills. The relationship with his son, which used to be an authoritarian one, has turned into a close friendship. His son calls him a housedad because J. does all the chores around the home and he enjoys it. He prepares most of the meals although he's still not a great chef. In the summer they took a driving holiday together. J.'s son drove and J. planned the itinerary and the route.

Problems with decision-making and memory persist. Family meetings are designed to allow J. to make suggestions to his wife and son and they propose alternate ideas, if necessary. Before making a decision, he tries to think about what they would say. He relies on their input to feel confident with his choices. He has to do a lot of planning in advance. For instance, he maps out a bus route or even visits a new location once before the actual appointment date. The memory problems affect all parts of his life. He forgets a lot of things. At 52 he likes to think this could be attributed in part to the natural aging process. He's not as young as he used to be but he knows the true source of his memory problems. The systems he has learned help him cope. His electronic diary keeps track of appointments and chores. He spends a lot of time planning and organizing so there are fewer surprises to have to deal with spontaneously.

He knows where he has to go, how to get there, and what comes next. He's able to successfully juggle a busy schedule this way.

J. is able to drive but it can be tough. One day he drove his son to the airport. He was following a friend who had brought his car to help carry the luggage. J. saw a mountie behind him putting his light on. The mountie was in the slow lane but accelerating. J. became confused because he was in the fast lane and he wanted to switch to the slow lane. J. speeded up to get ahead of the mountie and get into the slow lane. Instead of the other guy getting a ticket, J. was pulled over. The officer asked why he had passed him and J. explained that he wanted to get into the slow lane. The mountie pointed out that all he had to do was slow down and stay behind the patrol car. J. didn't tell the mountie it was because of a head injury, he just said he wasn't thinking. J.'s son was mad at him too. Afterward, J. was sure that a grade one child would have known what to do.

If he has one criticism of the treatment he received, it is that some of it was premature. Examples of this are his stressful driving lessons and his difficulties adjusting to the first home-based rehab worker. He did not realize the problems at the time. He was so motivated to get better, he wanted to do anything that was suggested.

J. maintains his self-defense training and is an enthusiastic amateur photographer. He drops in on his instructor from time to time. They go for coffee and discuss methods. He does volunteer work at several hospitals and that combined with his commitments to the Knights of Columbus and the Lions and his responsibilities at home leaves little wasted time in his day. He's happy with his life and his interests. He

wouldn't go back to work even if he was paid double. He understands now that he is not competent to handle the life and death responsibilities he assumed prior to his injury. He no longer misses it. Leave it to the young kids.

J. believes that one never recovers anatomically from TBI. But in terms of day to day living, it is a thing of the past for him. Adjustments have been made and his identity is not connected with his deficits. J. believes that acceptance, although a long process, is the key. Reviewing his medical textbooks over time helped him realize that he could easily have died or been more severely disabled. Once he began to believe that he was actually very fortunate, he was able to accept responsibility for his own recovery. Having his wife and son point out that his rehabilitation facility was not a prison but an opportunity helped him re-evaluate his time there. It was a gradual process but once he achieved acceptance, there was nothing left to haunt him. The pressure was off. "If there is not acceptance, forget it".

COMMENTARY

In the beginning, J. was completely disoriented and confused. He has few memories of the weeks following his injury. His violent behaviour led to him being restrained for his own protection. He was in a great deal of pain. As his awareness of his surroundings increased, he found himself in a position of helplessness and reliance. He was woken up, fed, bathed, told when to sleep, and told he could not return to work. When he spoke, no one understood him. This was not what a man who was intelligent, professional, and the head of his family was accustomed to.

For eleven months following his accident, J. was in hospital. The first couple of

months were primarily for physical recuperation. The rest of the time he was engaged in active rehabilitation. After discharge, rehabilitation activities remained central in his life. He did as he was told and relied on the structure to achieve a sense of accomplishment.

J.'s life roles changed dramatically following his accident. He needed constant care. He could not act as the father, husband, and provider he had been prior to sustaining the traumatic brain injury. In the rehabilitation hospital, he was like a child, being taught how to walk and talk and being told when to eat and sleep. At home, his rehabilitation worker referred to him as brain damaged despite his requests for other descriptors. He was unable to return to his position as a respiratory therapist at the hospital.

Certain events over the course of his recovery stood out for J. He remembered vividly the weekly Sunday ritual when he knew he had to return to the rehabilitation centre. He wanted to stay home but his life had changed. He was not the strong, independent person he used to be. J. looked forward to his discharge and return home. When it finally happened he felt weighted down by a sense of loss. He could not find any energy or motivation. He didn't know what to do with himself. He forgot a lot of things. It seemed like he had taken a large step backwards. It was not what he had expected.

As time passed he continued to encounter surprising obstacles. The behaviour that led to his getting a speeding ticket was humiliating. J. discovered that when he got nervous and had to act quickly, he struggled to make the right decision. Often, he did not.

J. was willing and determined to do whatever was needed to get better. He followed instructions and advice. As he became more familiar with his deficits, he tried to accept them and be patient with the length of the healing process.

One of the events that created a shift for J. was the challenge he received from his wife and son regarding his return each Sunday afternoon to the rehabilitation hospital. Up to that point he was feeling helpless. He felt like a prisoner there. Once he realized he had some control, that he could leave, he no longer wanted to. He was then able to embrace the experience. He returned to his room he became more aware of his roommate's dependence on others. By comparison, J. was mobile and getting better. Finding descriptions of his injury in his medical texts provided J. with objective information which supported the long recuperation period he was undergoing. Frustration gave way to patience.

Away from the routine of the rehab centre, J. found himself sleeping and watching television while he waited for his next rehab appointment. When the lifeskills worker suggested that he engage in some hobbies, he jumped at the opportunity. Expanding his repertoire of musical interests, taking up photography, and returning to martial arts classes gave him a reason to get up each morning. When he added volunteer work at the hospital, he had to learn time management skills to meet all his obligations. He was busy again and that made him happy.

J. later attended a social centre for people with TBI. Being reunited with other people with disabilities reminded him that he was very fortunate. J. saw no reason to feel sorry for himself because he was better off than many people he knew. He was able

to drive and ride the bus. He did volunteer work and hobbies. He was a member of the charity organizations and the church choir. He contributed to his family by attending to daily household chores, including meal preparation. He felt fortunate and grateful.

By the end of his story J. describes a harmonious engagement with the world. He is able to express himself and is understood by others. He knows what he is capable of and what brings him pleasure and meaning. He sticks to those activities.

He is very close to his son whom he treats as a friend. He has adapted to the changes in his relationship with his wife. He respects her decisions as head of the household and the primary earner. He has friends from his many outside hobbies and he enjoys his connections with the patients at the hospital.

J. looks back over the transition with satisfaction. He has said good-bye to his former career and he no longer thinks of himself as brain-injured. Everyday he is busy with activities which are meaningful and enjoyable. Everything he is doing, he is doing because he wants to. His involvement with his family, his church, his patients and his hobbies are all values that had been short changed before his accident. Now he cherishes them and he laughs easily and frequently. This is J.'s life.

CHAPTER VI

CASE STUDY THREE: G.S.

G. grew up on a farm. His father bred and trained racehorses. When G. wasn't on the farm, he was at the racetrack with his friend K. They loved to race against one another. G. graduated from high school in 1968 and took a job at a refinery. He picked that site because he wanted to be near the track. He was the third generation of horsemen in his family since they moved to Canada. Even before immigrating, his family had a long history of horse training.

At the refinery, G. was a station operator and he hoped to earn a promotion to superintendent. He married and had three children. The job afforded him the income necessary to support his family and pay for the expenses associated with the horses. He enjoyed the lifestyle, the independence. He drove to horse shows on long weekends and he bought whatever he needed in the way of equipment or clothes. He developed a reputation as a good worker and as a talented horseman. By gaining their confidence, he was able to make mean stallions act like pussycats and become good runners. He began assuming more responsibility for the farm as his father got older and he planned eventually to take over the business completely.

G. used to leave early for work so he'd be on the freeway before most of the traffic. He loved his truck. He drove it for 15 years without getting any points for driving infractions. When it got old, he put a second engine in it. It wasn't unusual to drive to Oakland and back to race on a long weekend. It had a lot of memories attached to it. When he arrived at work, he used the extra time to make sure his station was

ready to go. He wanted everything to be clean and lubricated so that his day would run smoothly and he could leave for the track at the end of his shift. G. organized his life carefully. He used a two year plan, sometimes even a five year plan. He knew just how long it would take him to pay off his latest purchase, a new horse trailer or pickup truck. He calculated the number of hours he needed to work at the refinery and the track to achieve his goal. Problems arose in G.'s marriage in the mid-80's. He was always working or training horses, not devoting much time to his wife or children. On the weekends he travelled to the U.S. for races. G.'s wife left him. He carried on with work and training.

One day in 1988 G. received a call from a wealthy man who wanted to learn about racehorses. The racing commission had referred him to G. because of his success and his family's long working association with horses. It fed G.'s ego to be recommended so he agreed to accompany the man to a horsemen's meeting. He has no recollection of the crash that occurred on the drive home from that meeting. He was told that his skull was crushed and one eye was hanging by the optic nerve. His hip and shoulder were also crushed. He required neurosurgery and a steel plate was implanted to serve as the top of his skull. He was told he was in a coma for a long time. Afterwards he had severe, unpredictable seizures. He needed assistance walking. G. has no recollection of this time. He was later informed that the driver received only minor injuries and returned to work within a couple of months.

When he was released from the hospital he went to recuperate on his dad's farm. He was in a lot of pain but he also felt tranquil being back there. Everything was slow

and laid back. There was no sense of urgency for anything. He was in the bedroom upstairs and he kind of felt like a kid again. His old bike was outside by the barn and there were warm childhood memories all around. He savoured the comfort and isolation, the enjoyment of being in a quiet place with trees and horses.

Friends and neighbours came to visit. There were a lot of religious people in the community and he found comfort in their quotations from the bible. They helped him understand. G.'s father took him by the arm and walked him slowly around the track where they trained the horses. G. wasn't worried about the running of the farm since the decisions concerning the horses, which races they would enter and which would be bred, had already been made for the season.

The neurosurgeon told G.'s father that his son would never be the same. He said that G. would always have partial brain damage and be slow. G. didn't accept that. He was optimistic, sure that things would be fine after a while. As soon as he felt physically able, G. went back to riding and training horses. Immediately, he began getting grief from the people around him. They said he wasn't putting the equipment on the horses properly. The trainers who used to learn from him said they couldn't trust him to do things right. They said he was missing steps. For instance, he forgot to put breastplates on horses so the saddles slipped. He exercised the horses in the mornings when there were up to 60 of them on the track. They claimed that if he lost control he could hurt other people. They told him that he couldn't ride any more. He couldn't believe it. He was sure he was doing everything properly but they said he was doing everything wrong. In 1989, the racing commission took away his license to train horses and his privileges to

ride them. For generations his family had been horsemen. That's who he was, a horseman. It was like having his heart ripped out.

Another blow came when his physicians took away his driving license. They said that his seizures made it unsafe for him and everyone else on the road. That was also difficult for G. He was sad and worried. He didn't know what was going to happen. He remained hopeful that he could get them back.

G. had a lot of doctors appointments and he was sent to a rehabilitation program. He didn't trust them. They told him things that weren't true. It seemed like there was a conspiracy against him. The neuropsychologist was his worst enemy. Sometimes his sister or a friend drove him places but they had lives of their own and he didn't want to impose. He used the Handidart service to get around. He needed his independence. To get to the places he used to drive to in ten minutes required an hour and a half travel plus another hour and a half waiting time. When he went to the track he could only stay 90 minutes because of the Handidart schedule. One time his sister drove him and his kids to the track to see G.'s father's horse run. The kids disappeared so he went to the information desk. The woman there reminded him that they had grown up at the track, that they knew exactly where they were. He realized the only thing that had changed was that he didn't know the place as well as he used to. Some parts of his life got erased during his neurosurgery.

G.'s doctors told him that he should never ride a horse or even be in the stall with one in case he had a seizure and the horse panicked. He couldn't ride and he couldn't spend any time with the horses. He lost the closeness with his old friend K. after they

stopped seeing each other and doing things together. G. stopped going to the racetrack.

G. tried going back to work in 1990. He didn't know he was being observed and analyzed by two of the superintendents that he had trained. He got injured a couple of times within a few days. He had a few seizures and that didn't go over very well. After a couple of months he had a meeting with the superintendents and they told him they had to let him go. They were afraid he was going to hurt himself or someone else. He felt awful. He disagreed with their assessment. He felt angry and betrayed. He started swearing at them. Then he was yelling and screaming. It seemed like everyone was against him, his bosses and co-workers, his friends and colleagues at the track, and even his doctors and rehabilitation professionals. He had trusted people at work and at the racetrack but he didn't trust them after his surgery. It seemed like everyone was trying to tell him he couldn't do something. Before the changes they used to leave him alone because he did so well and was so organized that nobody harassed him and life was simple. Then all of a sudden he was getting a whole bunch of grief and he didn't like it. He felt bitter.

Later, he had a meeting with his superintendents and apologized for getting mad. They explained that he had trouble with the sequence of starting the machines and the conveyors. G. was confident of his skills but was shown he was missing many of the steps. The superintendent showed him a journal written about how to run that station. Asked if it was familiar, G. said it wasn't. He was invited to look at the name of the person who wrote it. There was G.'s name. It was quite a shock. After that he knew something was wrong.

It was a time of great turmoil for G. He'd lost his riding/training license, lost his driver's license, and lost his job. G. thought about the people he'd known and depended on in the past. They had shown him proof of his mistakes. He trusted the superintendent because G. had trained him and knew he did things well. He decided that people don't take things away from you unless there is a good reason. He eventually concluded that he was no longer the same person he used to be, that he was quite different.

He came to the same conclusion regarding the people he trusted at the racing commission. He was sure it hurt them to take away his license but they observed him all the time and pointed out what he was doing wrong. He reflected on his actions, and what they had shown him, and he knew that he had been making mistakes. The horses were so well trained that they tolerated him. Unfamiliar horses probably wouldn't have. The mistakes he was making never would have occurred prior to his injury. He knew they must be right.

A couple of people from work came by at Christmas for the first year or two but he knew he'd lost his friends from work and from the track. They didn't want him around the track or the refinery because he could hurt himself. Some of his friends referred to him as brain-damaged and that hurt him. He didn't like being there any more because he wasn't wanted. He felt like a stranger in the places he used to live.

The changes were also hard on G.'s father. He was getting older and G. used to make a lot of the decisions about their horses. After G.'s injury his father started losing money. He began making bad decisions. G. was unable to do anything about it because

he was struggling with his own problems. G. realized that his father had seen his errors too but didn't have the heart to tell his son. He wasn't sure how his son would take it.

His neurologist explained that he would never be the same and his psychiatrist and physician said the same thing. G. realized he would just have to accept what's going on and live his life the best he could with the medical problems that remained. That was the way it was going to be. He'd just have to live with it and do the best he could. He could fight it and make life miserable or he could accept it and keep himself as busy as possible.

Christian friends made a difference in G.'s life. One friend was a missionary. He stayed with G. and his father when he was visiting. He talked to G. about his work abroad. G. began to see things differently. Prior to his injury, he didn't have a personal faith but he had studied various belief systems. At his friends' encouragement he went to a Christian church. Over time he developed a relationship with God. He couldn't think about a lot of things he read but he remembered certain verses. That was enough to count on when there was nothing else. "They that wait upon our lord shall renew their strength, they shall mount up with wings as eagles, they shall run and not be weary, and they shall walk and not faint." Here he was broken, not expecting a very good future, and unable to walk properly or ride again. The words of the verse moved him. He drew strength from them. He was able to give his frustration to Jesus while he worked on just getting through the rest of the day. Faith in his God became a central part of his journey.

G. was constantly facing previously attained skills and knowledge that he had lost.

He began to wonder if there were different things that he could learn. In 1993, G. applied for college admittance. His cognitive therapist helped him prepare during the months before the entrance exam. She knew the type of questions to work on. The lifeskills worker drove him to the exam. G. sat down amongst a room full of smart young kids and he did really well. He felt proud. The cognitive therapist helped him enrol and he started with a course in English. Again the cognitive therapist and lifeskills worker helped him with his assignments and he realized he could trust them. They made a difference in his life because they were really stable people and it helped being around them. They arranged for a student tutor to work with him. He used audiotapes of books because of his visual problems, which worsened with medication and fatigue. He felt really disappointed with the C+ grade he got in his first English course. He found it hard to put his thoughts and ideas into an essay format but the tutor helped. He went on to an English 200 course which he also passed.

In 1994, G.'s father, who was 88 years old, went bankrupt and they lost the farm. G. missed the open spaces and more than anything, he missed the horses. The last one went to Saskatchewan, eliminating the possibility of his ever seeing it run. The farm that he had expected to take over from his father, the house he grew up in, the horses he loved, the lifestyle and family tradition, were all gone.

In 1995, G. sold his truck. Despite his hope that he would drive it one day, results from neurological tests indicated that he should not drive. He was still having seizures so it was not realistic to want to drive. He sold the truck within a month. He figured there was no use living in the past and if he started dwelling on the it, he'd get

sick. Letting it go fit with his philosophy to live in the present and acknowledge his restrictions. The extra money helped pay some bills. Still, G. found it difficult to part with the vehicle. It represented so much of his past and selling it was like saying goodbye to the future he had wanted and expected.

G. carried on with college courses and completed five. On one exam he got zero, which was terribly disappointing. A C- for the last course bothered him. It felt like a fail. He wants to do higher level courses despite the fact he cannot pursue a career. His doctors told him that he's unable to work anywhere because he tires too easily. Even with the disappointments, G. believes that taking a course is better than sitting around feeling sorry for himself or waiting for the next seizure. It gets him out of the house and interacting with other people. He found that some people in his English classes got closer to him when he allowed his emotions to be expressed in his writing. Classmates were crying as he described the pain of losing his horses when the farm was taken.

G. says he couldn't understand what had happened to him for a long time. Today he can recognize his limitations and knows he can't do too much physically or mentally. He used to be able to focus on a whole bunch of things at one time whereas now he can only focus on one thing at a time. He's not as quick as he used to be. He walks with a cane. The many medications he has to take cause side effects such as headaches, increased fatigue, and blurred vision. He tires easily and he has to write down appointments so he doesn't forget them. He has trouble sequencing and organizing his thoughts. He's accepted the fact that his seizures could lead to a stroke. He has put his house in order. He lives in his father's home on a fixed income. With budgeting habits

and guidelines set up with the lifeskills worker, he can just manage.

G.'s father is in hospital after suffering a stroke. His teenagers are around quite a bit but at times they're angry. He thinks they're ashamed of him. They're about the only people who come around. G. really misses his old friend, K. When he sees him he wants to go up to him and give him a hug but K. would probably find that really offensive. K. is very polite to him, very civil but he's not the same. G. figures that people assume that since he is disabled, he will make disabled friends. He's heard that K. is doing well and knows he has his own life to live. He hasn't seen him for a long time. The same goes for all the others he used to enjoy working with at the refinery and at the track. Nobody comes around any more. He just lost them. All the people he enjoyed and respected. If he allows himself to think about it, it hurts. Its hard to talk about it. So he does the best he can. He's discovered that he can't fight things. If he starts complaining or getting bitter, he'll only destroy himself.

The challenges of daily living distract him from the things he cannot change. He just received a bill from his lawyer for \$5,000. The legal hassles bother him. He recalls a time when he would have completely panicked over such a bill. All he wants is for the case to be resolved in a positive way but he's come to realize that it may carry on for some time to come. He reminds himself that he just has to take it one day at a time.

COMMENTARY

For a long time, G. had no idea what happened to him or what the impact would be. He was happy to be at his father's farm and confident that he would recover and go back to his old lifestyle. The extent of his injury was well hidden from him.

Once he began resuming old activities he was struck by clashing constructions of reality. He was confident as he carried out standard tasks at work and with the horses. But, people he trusted told him he couldn't drive, ride or train horses, or do his job. He was deprived of his right to do all of these things for no apparent reason. It really seemed like everyone he knew was engaged in a huge conspiracy against him. Despite the conspiracy, G. was not about to give up on himself. He intended to get his riding/training license back and he kept his truck in anticipation of the return of his driving license. It made him angry when people said he was doing things wrong but he wasn't going to get pushed around. Since he couldn't drive, he used the Handidart. It was a lot slower but at least he could get places on his own. He rode to his rehabilitation that way but he couldn't trust them. They were telling him things and he knew that wasn't the way they were.

All of G.'s significant relationships changed. He was watched by his own trainees, both at work and at the track. He was helped by his elderly father just at time when he had been assuming greater control over the family business. He wasn't able to take care of his children in the same way. Some friends came to visit for a while but he couldn't do the same things with them that he used to do.

G. was stunned when he was shown the work station manual that he had written. He was sure he was doing his job properly and he had no recollection of there even being a manual. The fact that it was shown to him by someone he trusted forced him to reassess his situation. Similarly, he was shown his errors at the track by people he had known a long time. Once he knew he had missed things at work, he realized the same

thing was happening at the track. The permanence of these changes was brought home in conversations with his neurologist, physician and psychiatrist. The experience of losing his children at the racetrack also had a profound effect on G. His worry regarding their safety turned into recognition that the problem lay within him. The confidence and assurance of the woman at the information booth served to highlight his own disorientation and loss.

The loss of the family farm marked the end of a tradition and the end of a dream for G. The family history of training horses and passing the skills and responsibility on to the next generation ended there. The horses that G. loved were sold and with that his identity changed. The sale of his truck was also symbolic of an ending. It was more than just a vehicle to G. and he had kept it in hopes of driving it again some day. Once he knew that would not happen, he let it go.

The words of the bible as spoken by friends and neighbours soothed G. during his early recuperation. Later, he took their advice and began attending a Christian church. He read the bible when he could and remembered as much as he was able. Over time he developed a belief that sustained him through some of the really hard times. He shared his pain and that helped him get by.

Another turning point for G. was the college entrance exam. This was a whole new experience for him. He had never really considered himself college material and it was exciting to be trying. Despite his age, his injury, and the years since he finished high school, he passed the exam and entered a new world. Starting a college course was exciting and tough. He needed help to learn the material and produce reports but he

enjoyed going and learning again.

By the end of his story, G. had come to terms with his disability. The clashing constructions of reality have ceased. He realized that he can approach a task with confidence but make many errors without realizing. He knows that he forgets things and so he has to write them down. G. feels quite alone in his life. His friends stopped visiting. His father became very ill and had to stay in hospital. His children don't treat him the same way. They don't ask his advice.

Some of G.'s satisfaction with himself comes from his acceptance of his situation. His psychiatrist taught him that most people he sees have problems because they don't admit the truth to themselves. They go on deceiving themselves that they're going to get better and that things are going to be exactly the same as they used to be. The doctor expressed respect for G.'s willingness to acknowledge and accept that things will never be the same. The doctor treated a lot of people so he came to that conclusion based on a lot of interviews over a number of years. And he saw G. for a lot of years so he knew him well. G. trusts him.

G. has doctor's appointments and he takes one college course when he can. Going to class gets him out of the house and involved with other people. The homework is difficult. Its hard to concentrate for long and putting his thoughts into an essay is a struggle. Still, it seems a better alternative to staying at home alone.

His life seems pretty stable at this point. He doesn't foresee any big changes. He knows that the seizures will continue and may become fatal. He wants to do more than sit and wait for that to happen.

CHAPTER VII

CASE STUDY FOUR: S.P.

S. grew up in a small community with her parents, her twin sister, and two other sisters. Her parents separated when she was young and her father's family cut all ties with S., her mother, and her sisters. When her mother remarried, S. developed a close relationship with her stepfather. She called him Dad, a term of honour and affection.

S.'s biological father was an alcoholic and after the divorce he contacted S. from time to time when he was feeling guilty. She called him occasionally to tell him how she was doing. At 16 she spent six months living with an aunt in the states and going to school there. She came home to find her mother drinking excessively. S. quit school two weeks before graduation and moved across the province to help her twin sister manage an unplanned pregnancy. She got a job as a live-in housekeeper and driver for an elderly man. S. and her twin were not close. They were described as "night and day", "good and bad". S. was always helping her sister but getting nothing in return. S. was the giving one and her mother and sister came to her for advice. She was the rescuer.

Eventually S. returned home. She tried a variety of jobs. She was a painter and a janitor, a bartender, a waitress, a short-order cook, and a supervisor of housekeeping at a resort hotel. The problems at home persisted so she moved out with her younger sister. By then her weight, which had been increasing since she was 13 years old, reached 350 pounds. She quit her job and spent her time going to bars and drinking a lot. She was depressed and leading a directionless lifestyle. She was looking for

something but she could never find it. She was very unhappy.

In February, 1989 S. was driving to the bar when her car hit black ice and skidded into a telephone pole. She was in a coma for two and a half months. She regained consciousness a week before her 22nd birthday. Just after she emerged from the coma, she was transferred to a hospital in her own community. S. was placed on a geriatric ward.

S. had to go through everything a baby goes through. She wore diapers and had to learn how to eat and speak. Her right arm had curled up to her chest. Her first memory is of the day she started talking. The nurses wheeled her whole bed to the phone so she could call her mother and say hello. After a few weeks she was able to go in her wheelchair to the pay phones and call home. Her parents always left dozens of quarters for her. Lots of people came to visit her and they signed a guest book so she could look at it later. Her friends wrote their phone numbers in it so she could call them.

The physical rehabilitation was terribly frustrating because she knew in her head what to do but she just couldn't get her body to do it. The muscles wouldn't work with the brain. She got really pissed off. Sometimes her legs shook uncontrollably. It hurt but worse than that was not knowing why, what she had done to deserve this.

She lost her beautiful long hair. The doctors had to shave one side of her head when they performed the neurosurgery. She cried about it and ask her dad where her hair was. He reassured her that it would grow back. S. also discovered that she couldn't wink. When a good looking doctor or orderly went by she thought she was winking at

him until her dad told her she wasn't. He taught her to wink again. This was a highlight in her recovery. Ever since she had emerged from the coma, she had been confronted with what she could not do. Relearning to wink was a big deal because it was something she could do by herself. She also learned to shuffle cards and play crib again.

S. did not see a future for herself. She was in a wheelchair and painfully aware of what she could not do. During her hospitalization the nurses went on strike and her mother had to come to the hospital every day to feed and shower her daughter. S. felt helpless and hopeless. When she was discharged she spent one month at her parent's home. Her father wanted her to stay with him but her stepmother did not want an invalid in the house. S. then entered a rehabilitation hospital where she lived for the next three months. One of her accomplishments there was to straighten her right arm but when she left she was still unable to walk.

The next thirteen long months (from January, 1990 to February, 1991) were spent in a private rehabilitation house. She hated being there. She was given some preliminary instruction for physical and speech therapy and then left to pursue the program on her own. Despite housing only four residents and a few outpatients, it was very impersonal and lonely. S. wanted to be at home and with her friends. Once in a while her sister picked her up and took her to her parents home for the weekend but visits were rare. Perhaps the drive was too long. When they did come, S. laid a guilt trip on them. She was glad to see them but she also felt angry and abandoned. She hated herself and her life. She couldn't walk and she hated her wheelchair. She saw her twin sister and felt jealous that she could go out with friends while S. stayed alone in the city. When she

was with her sister and other people, they treated her like an invalid. Her sister used it to advantage to get into bars. She took S. to the front of the line and told the bouncers to let her in with her handicapped sister. S. felt small and degraded. She was in a wheelchair but she still had a mind. During this time, S.'s grandmother died and not long afterwards her father, a longtime alcoholic, put a gun to his head and pulled the trigger.

When she left the group home, S. was placed in a bachelor apartment. She had financial support from her insurance company and an occupational therapist who got her on the priority lists for subsidized housing. She had some very dark times there. She was so depressed she would go to her medicine cabinet, look at her prescription medications and think "I can't live like this no more". She felt completely restricted by her wheelchair and didn't know if she would ever get out of it. She placed little faith in the opinion of medical experts. One friend had told her that 'ex' meant 'has been' and 'spert' was a 'drip under pressure'. She didn't believe that head injuries could be categorized or outcome predicted. Part of her depression came from the realization she was 23 years old and she had always dreamt of getting married and having kids. The dream wasn't happening. She was cut off from friends and distanced by her family. She treasured the occasional visits but wished she could return to her hometown so she could feel more connected. She felt terribly hopeless and wondered why she should live. Nobody seemed to miss her and if they did, they could just look at her twin sister. S. was afraid to go ahead with suicide but she also knew that it took more courage to live.

A couple of job trials were arranged for S. She worked at a daycare but was told

that she was not allowed to be alone with the children. That was really discouraging and made her feel like she didn't want to be around children. Later she was sent to a flower shop. She sat in her wheelchair and made arrangements in baskets. She wasn't paid so they gave her some baskets. She made them up and gave them as gifts. She loved it. Still, as each trial ended, she was left not knowing what she could do to earn a living for herself.

During this time, she met a man and began a relationship with him. He said he didn't want to have children. S. was afraid he would leave her so she decided to get her tubes tied. Over time, problems arose in their relationship and eventually it ended. However, S. had come to realize that just because she was in a wheelchair, life hadn't stopped. She felt more attractive and she began to believe that the right person was out there for her.

S. moved to a one bedroom apartment in October, 1991. Most of the residents were elderly people. They spoiled her and encouraged her to walk. One of her neighbours was paraplegic. He was independent and didn't seem to be restricted by his wheelchair. He drove a car which was inspiring for S. She realized that she would be able to drive again as well. The people around her were interested and encouraging and she had a role model. Where her family had let her down, these people were there for her.

Within a few months S. stopped using her wheelchair at home. It was scary to take that step but using it could be frightening too. One day she crossed the street and fell right out of the chair in the middle of the intersection. Eight months later, against

her doctor's advise, she sold it. She found that if it was there, she used it. The extra dollars didn't hurt either. She got a good price and bought an oak cabinet with the money. She looked at the cabinet and said, "this is my wheelchair". Next she tried going out without her cane but she lost her balance on the bus and fell to the floor. From then on she used her cane when she went out.

As she reflects on her journey, S. concludes that staying in the city and not being allowed to return to her community prevented her from falling into the same rut she was in prior to her injury. She hated her parents for making her stay there but now believes it was the best decision for her. She wasn't in a position to really know what was best for herself at that time.

S. has been in a serious relationship since December 1994. They are engaged to be married in the spring of 1996 and she is excited about this new step in her life. She will be living her dream to have her dad walk her down the aisle and give her away to her future husband. She is optimistic they can overcome the problems which challenge married couples in general, and those with brain injuries in particular. S. is getting help controlling the anger which contributed to verbal and physical violence in their relationship. She is learning that she has always felt it but that it was hidden beneath a kind, caring, and giving person. She believes moodiness and self-centredness are also obstacles for her and others with TBI.

She has developed other skills for daily living. For instance, she can write out a budget and follow it. She has come to terms with her restricted mobility and makes sure she takes her cane if she is riding the bus. She uses written reminders so she doesn't

forget important appointments or ideas.

Her relationship with her parents and sisters is strained. She feels ignored by them because they see her as their daughter/sister with a brain injury. She feels judged by them. She resents the fact that they weren't there for her over the course of her recovery and that they are still not supportive. S. says that her own self-centredness has subsided and she regrets the guilt trips she laid on her family when she was at the residential home. She knows now they had their lives to lead too. By understanding herself better, she can see her family in a different light. Her mother struggles with a 'poor-me' syndrome that's gotten worse and her twin sister continues her selfish and self-destructive lifestyle. It's their current behaviour that confirms S.'s assessment of her family. Her fiancé's family phone and visit and share holidays such as Thanksgiving and Christmas. S. hears nothing from her own family. If she wants to speak to her sisters, she has to call them. Despite the problems, she believes that if there was a crisis in her life and she asked for help, they would be there.

She is all too aware of the role of alcohol in her family history. Her alcoholic father committed suicide and her mother, stepfather, and grandfather are recovering alcoholics. She was losing her fight against alcohol before her crash. Now she drinks far less. She doesn't believe the notion that people with TBI shouldn't drink. She hasn't seen any proof that the risk is any different than for anyone who abuses alcohol. With or without TBI, she knows the damage that alcohol can inflict.

S.'s first relationship with G. was a turning point in her recovery. She began to feel better about herself and realized that she could be in relationships, and that her

dream of marriage and a family was not unreachable. With her fiancé, she's excited about their future together and cautiously hopeful that they might have children. On the other hand, she's aware of the difficulties which can threaten their happiness. Her parents stressed independence and she has learned to live that way. It can be hard adapting that to interdependence with a partner. They've made a commitment and are both working hard to manage their behaviour and stabilize the relationship.

Her faith was also significant in her recovery. S. believes she would not have survived initially without her faith in God and the prayers of friends and family. Later on it made a big difference when she was feeling alone in the world and hopeless regarding her future. "If all else fails, pray".

When she considers the rehabilitation treatment she received, S. identifies money as a central theme. First the nurses went on strike, an event which served to highlight her own helplessness. The wisdom and the impact of placing a 22-year old on a geriatric ward remains a question in her mind. On the bright side, it was good training for her future accommodations in an apartment block full of elderly residents. S. felt she was rushed through at the rehab hospital and is still shocked to think that she had not learned to walk when she was discharged. There was a lot more improvement she could have made before leaving. She is equally convinced that a great deal of her rehabilitation money was wasted at the residential facility. She was offered little of value and certainly not thirteen months worth. Mostly she was left to do things on her own. At \$3,300 per month she doesn't believe she or the fee payers got their money's worth. She experienced rehabilitation as a way in which other people make money.

S. admits her own strength in working her way back from TBI. She wonders what it would have been like if the accident happened to her twin. She thinks her sister, a person who relies on others, would still be in wheelchair. She believes that her inner strength is an important ingredient in her recovery. For S. it is often expressed in her sense of humour, seeing the lighter side and laughing are ways she copes with the tough stuff.

Some struggles persist. She continues to battle with food and her weight. She wonders if she can work. From age 13 until just before her accident she was always employed at something, generally physical work. Since she still suffers from headaches, arthritis, and bad back and knees, physical labour is no longer an option. She didn't graduate from high school so that limits her prospects. She receives \$359 per month to live on. She has a strict budget and barely makes it from month to month. She really wants to learn to drive again but there is no funding and no way she can afford the lessons.

As she contemplates her story, S. says that one is never totally recovered. There's always something new every day. She remarks that this may not be so different from the experiences of those without TBI. She wouldn't wish her life before her accident on her worst enemy. Since then, it's gone from bad to great. Life is a learning process. Six years after her injury, S. succeeded in getting her body to follow her brain's instruction to jump. Now she has both the desire and the ability to jump for joy.

COMMENTARY

S. lost two and a half months of her life during her coma. When she emerged from it, she was not able to understand or remember much of what was going on around her. She was told that when she first awoke, her grandmother asked her if she knew who she was. She responded with, "of course, you're my grandmother, don't be so stupid". However, if not for the guestbook that friends and family wrote in, S. would not have known who visited her and when. She doesn't remember being discharged from the hospital and little of the time she spent at the rehab centre. One winter day she was driving to the bar and the next thing she knows, her spring birthday has come and gone.

As her awareness increased, so did her confusion. She thought she was winking at orderlies and doctors but was told she couldn't wink at all. She wondered why her beautiful hair was missing on one side of her head and why her legs kept shaking. She was an adult but she had to wear diapers, learn how to eat, and learn how to talk. She knew in her head, but it wasn't working. When she started learning how to walk, she had to learn to crawl first. She swore at her therapist because she knew how but she just couldn't do it. It really pissed her off. She told her friends, "I can do it, I can do it, I know it!" but she tried and she couldn't do it.

S. wanted to go home and spend time with her sisters and her friends but was told she couldn't. She was willing to pay anything for her sister to help her do that. She just wanted to go the bar and spend time with her friends. It was hard to stay in the rehab centres because progress was so slow and she felt so alone. She wanted to walk but she couldn't even when she left the centre after three months. When she arrived at a small

residential treatment home, she expected more structured and personal contact. Instead she felt even more alone when left in charge of following her program on her own. S. was convinced that everything she accomplished could have been done in six or eight months instead of thirteen. She could accept no for an answer if she felt like someone had listened to her. She wanted to be at home but if she couldn't be, she wanted to know that she was making real progress. She had neither.

Family relationships had been strained for a long time but as a caregiver and rescuer of family members, S. assumed that they would be there for her if she needed them. Instead she felt abandoned and neglected. When she contemplated suicide, she believed they wouldn't miss her at all, particularly since she had a twin. On the few occasions they brought her home, S. was treated like a child and a invalid. She had a mind but they saw a wheelchair.

Before her injury S. was independent. She worked so she could live away from home and pay for her lifestyle in the bars with friends. Afterwards, it was her twin who was going out drinking with friends while S. was alone and in a wheelchair. As time passed she started thinking about suicide as an option. She didn't want to die, she just didn't want to live without hope. She couldn't walk, she couldn't go home or go out with her friends, she wasn't desirable to men, her family had scattered and she couldn't foresee anything changing for the better. S. didn't know which pills in her medicine cabinet would kill her.

Earlier in her recovery, before she lost hope, S. had worked hard to reclaim parts of her lost self. She got her dad to teach her to wink. There were some cute men in the

hospital and she needed that skill. She practised shuffling cards and re-learned to play crib. She found a name to describe the awful sensation of uncontrollable shaking in her legs. Just the word 'heebeejeebees' made her laugh and helped her cope.

S.'s life changed dramatically when she met a man who wanted to date her. Hope of fulfilling her dream returned. She discovered that she was attractive even though she was in a wheelchair. Positive forces in her life continued with her move to an apartment building filled with caring, supportive people and a role model for self-acceptance and independence with a disability. Seeing a man with paraplegia drive changed her way of thinking.

For several years S. wanted to get home to her friends. However, finding a good place to live and meeting the man she would marry changed her views. She realized that staying away was the best thing that could have happened. She knows she would have returned to a deadend lifestyle. This way she was forced to make a new life. Through her relationship with her fiancé, S. learned that she had to get a handle on her anger. She sought help to increase her self-awareness and develop new skills. Working at this together strengthened their commitment to make the relationship work. S. knew her dream was going to come true and she was working to make it successful.

S.'s heightened self-insight and change of lifestyle caused her to view her family differently. Without the anger in the way, she was able to accept their limitations and their own needs. She realized that each one is struggling with their own problems and S. is not there to rescue them any more. It's still difficult when they tell her what to do and treat her like a child but she makes her own decisions now.

S.'s focus is on herself and her fiancé. They care about each other and they help each other. She knows what she can do. There aren't so many surprises. She tries to be strong when her family interferes with her relationship. She asserts herself and insists on it between him and her and God. She's happy to be getting married and will have children, if God is willing.

S. feels much better about herself and her life now than she did before her crash. There are still things to work on such as herself, her weight, her anger, money matters, her physical pain, and her relationship. She thinks those concerns are like the ones that everyone else has, with or without a brain injury.

CHAPTER VIII

CASE STUDY FIVE: I.G.

I.G. is a 53 year old woman who raised four children as a single parent and worked full-time to support her family. She took some university courses prior to her marriage but could not return to complete her degree until her youngest child entered in high school. She received a bachelors degree in business management in 1987, the same year her older daughter graduated from university. When I. escorted her younger daughter to Vancouver to attend UBC, she decided to move back to B.C. She found work at a private youth school as a counsellor. She later added a job as coordinator for a social service agency. Eighteen months after that she accepted a new job as a family counsellor and then working with youth at risk in the schools. When funding ran out, she returned to family counselling. At the same time she began a high level administrative position in which she was responsible for a series of groups homes. She gave up the family counselling position to devote her energy to this new position. I. worked long hours but made sure that her week included time for fitness classes, swimming, hiking and enjoying the arts and her friends. She was close to her sister and attended the birth of her nephew. Her life included her role as a mother, sister, daughter and aunt. She was competent, independent and relatively happy.

On October 25, 1992, three weeks into her new job, I. went hiking with her club. She drove to the trail, left her car at a depot and got a ride to the trail head with a co-hiker. The description of what happened to her next came from accounts by other people. The group proceeded to hike up the mountain. They reached the peak where

they enjoyed their accomplishment and the view. She then initiated her descent down a challenging trail despite a warning not to go that way. She was some distance behind the person she was following when she fell. At first no one realized she was missing. Eventually some of her friends who were further down the trail spotted where she had tumbled down the mountainside. They finally reached her, administered first aid, and phoned for help. She was airlifted to a nearby hospital and immediately transferred to a major centre. The severity of her head injuries lead specialists to conclude she was not likely to survive. Her children and family gathered around her. Two doctors refused to operate because of her prognosis but a third decided to proceed with neurosurgery. She lay in a coma for two weeks.

She has minimal recollection of the weeks after she regained consciousness. She ripped all of the tubes and needles out of her body. Awareness of her surroundings and her ability to rationalize came and went. Her sister arrived from South America at the beginning of December 1992, but I. wished her away, she didn't want to see her. She refused to acknowledge her infant nephew. There were windows of clarity and memory. She did some neurological tests, spoke with her roommate in the hospital, and got out of her wheelchair and pushed it aside. She was released from hospital in mid-December, almost two months after her fall, and went to stay with her mother and daughter. When she was allowed to spend some time in her own apartment, she puttered away the morning and had large chunks of time that she had difficulty accounting for. Some afternoons she wondered why she was still lying in bed. She'd try to do some knitting and end up accomplishing nothing. She tried to pick up some of the threads of her life

but she couldn't seem to thrive. She was surviving, little more. She was wandering aimlessly in her life. She felt desperate. Everything had changed so much she wished she had not lived.

Six weeks after her hospital discharge, she entered an in-patient rehabilitation centre. She thrived on the physiotherapy but detested the occupational therapy. She had many tearful meetings with the occupational therapist whom she considered useless. She was obliged to do the same tests over and over and she followed the instructions but the OT contradicted her. I. just wanted her to get off her case. In physio, she was left to follow her own program. She used to go out into the courtyard and shoot baskets for hours on end, trying to improve her eyesight. She enjoyed the physical activity. I. became obsessive-compulsive, concerned about what she put in her body and she began reducing her intake of food and liquid until she became anorexic. She attended groups where they had to remember each others names and the day of the week and act in skits. She had to steel herself to attend. All she was doing was existing.

The person who became the most important during her stay there was a kitchen server. She always smiled and stopped to talk to I. She was the only one to whom I. read some of the prose she had written. The verses spoke of plans frittered away or not pursued. She made other friends that she really valued at the centre. There was a woman on her floor who had a lot of seizures and a man upstairs. Even so, I. felt like she was living in a vacuum.

When she left the rehab centre, I. was placed with her younger sister's family. This was difficult for her. She lost much of her independence. Later another sister and

her family arrived to stay as well. The hospital staff, her son, and her daughter told her she must adjust to her condition. They told her to go to a community centre or women's centre. It was an ordeal just to try to plan it. She felt great when she swam so she arranged to go to the pool but she rarely followed through. She couldn't seem to plan and act. She lost track of time easily. Sometimes she went into the bathroom to take a bath and brush her teeth and emerged to find three or four hours had passed. She spent a lot of her time at her mother's home. Her mother prepared food and insisted her daughter eat it. Otherwise time passed without her eating at all. She planned to go to bed early but didn't get there until 4:00 in the morning. She wasted time phenomenally, particularly at night. Left to her own devices, it was easy to do nothing and to eat nothing.

At times, I. wishes she had not survived. It could all have been over, without her knowing, if she had died in the first place. She would not have had to endure such pain ever since. Life wouldn't be dragging on and on. She wants to live but there are periods when the sheer effort of surviving is a terrible ordeal. She can't make a cohesive plan or execute a set of actions. Things just slip through her fingers, they get beyond her. It feels like she is progressing backward continually. She doesn't mind not returning to her job. She doesn't have anything more to prove there but she still wants to achieve something. She thinks of her career and her pre-injury lifestyle as a missing link in her life. She used to thrive on activity and accomplishment. Now they are so elusive. The value of life seems unreachable.

I. believes the recovery programs neglect the importance of motivating people by

structuring individually meaningful tasks which stimulate them. What is meaningful to someone else may not be meaningful to I. It is essential to consider the vastly different circumstances of each individual. She was told that she has to take care of herself before she can commit to outside activities. But it is the chicken and the egg syndrome. Taking care of herself, when there isn't something more, is extremely difficult. She gets fed up with the mediocrity of it. She knows she needs more and she has ideas some ideas but she can't put them together in a cohesive package. She believes that two or three structured days per week would be her limit but it would help her grapple with other aspects of her recovery, such as having a reason to get up in the morning and keeping track of time and making sure she eats. The knowledge of how to be a self-sufficient person doesn't necessarily translate into the ability to be one. She knows that a positive atmosphere contributes to recovery. She believes there needs to be practical involvement with people treated as individuals living in vastly different circumstances. Overall, the experience in the rehab centre has left her feeling angry because so much more could have been done. To this day she bristles when she's told "that's part of you, that's your condition". She doesn't know what her condition is, she doesn't know anything.

Today she simply doesn't know how to make sense out of what is left for her to do or where she belongs. She blames herself for a lack of willpower and perseverance, for not structuring her days well. The fact that she doesn't get to the aquatic centre haunts her. It used to be her training pool. Her psychiatrist explains these are symptoms of her injury and she must adapt to them. She understands this to a certain point but she needs to feel some sense of control in her life.

I. wants to work but she's been told that she will lose her disability pension if she takes part-time employment. The pension isn't a lot of money but it covers the cost of her medications. Her son warned her that if she doesn't improve her self-care, she will end up in a group home. She feels like the slowest and dumbest of them all. Then she's shocked when her doctor refers to her as bright. Holding onto the idea of herself as an intelligent person is a losing battle.

As she reviews people's descriptions of her behaviour in the early stages of her recovery, she struggles to understand herself, then and now. Her treatment in hospital of her sister and her nephew hurts very much to think about. Some things are hard to assess because she doesn't know which of her memories are made up and which are factual. As she looks ahead, she sees a long way to go. Too much of her life is in stasis and she doesn't know how to make sense of what is left for her to do.

On top of it all, new problems arise. In the spring of 1995 she was struck by a car while crossing the street. This impaired her walking ability and dashed her hopes of entering a 10 kilometre run. I. is trying to get into a subsidized housing program and make decisions about living here or moving in with her daughter on the prairies. Life seems to be a balancing act. She must try to attend to details but without going overboard and getting shut down completely. It is an effort for her to put one cohesive step after another cohesive step. She hopes that one day, with some editing help, she will publish her verses and share them with her friends. "I still in some way keep hoping to be able to leave some mark".

COMMENTARY

The weeks following her hiking accident are a blur to I. She came in and out of awareness in the hospital, not knowing what had happened and why she was there. She dismissed people she cared about. Her actions were out of character and full of distress.

For a strong and capable woman the restrictions and obligations she faced were shocking. She was told she could not live alone. She was given tests over and over and when she complied she was told she had not followed the instructions. She was forced to abide by the rules of someone she did not respect and who had less education and training than she did. She was told to get on with her life without knowing what the problem was or how to resolve it. She tried to return to swimming and running but encountered difficulties that were novel to her. She wanted to take work, to take on a new challenge but was told she could not do that for financial reasons and because she had not demonstrated an ability to maintain acceptable self-care.

I. tried to overcome her inertia by making arrangements in advance but it didn't seem to help. Her sister gave her a watch to help keep track of time but I. sometimes removed the battery so it wouldn't run down. Entering a rehabilitation program was also difficult. On the one hand she cherished her privacy and wanted to be left alone but on the other hand she expected more structure and more practical help. She felt angry and disappointed that she didn't find a positive atmosphere conducive to recovery. She was convinced that a great deal more could have been done to promote improvement in her situation. Instead she emerged still requiring help from those around her. She had to be cared for by her mother, her siblings and her own children.

I. was accustomed to independence. Having to live with family members was not what she expected in her life. She was horrified when she realized she was still in bed in the afternoon. Here was a woman who raised her children and often worked more than one job. She was active and productive but discovered that she couldn't get her day started. Time passed and she achieved nothing. She wanted a project, something that she was good at so she began making a baby blanket for her newborn niece but eleven months later it remains unfinished. I. thought of herself as an intelligent person but when her son suggested she would go to a group home she felt dumb, like she'd lost those qualities she valued in herself. She struggled to make progress but it didn't seem to work. When she was struck down by a vehicle her setbacks became physical as well as mental.

Out of the confusion, I. identified a goal to strive for. Upon reflection she could recognize a pattern of obsessing over details and losing the bigger picture. She tried to remind herself not to forget the details but also to maintain some distance so they did not become all encompassing. She also attached importance to the verses she wrote. As well as a creative form of expression, she hoped they might be of some value to others, a contribution she could make.

Three years after her brain injury, I. found life difficult and with little reward. She couldn't rely on herself to accomplish even basic tasks. She felt pressure from people around her but didn't have the tools to create the change they demanded. She wasn't sure who she was or what she was capable of doing. She had contact with her family but she still felt isolated and withdrawn. She wasn't happy with herself and that

affected her desire to seek out others. She was doing very little and none of it felt meaningful to her. Activities that might be of value were out of reach. Her inner turmoil and outer conflicts left her unsure where to live, what to do, or how to find meaning and motivation to live.

CHAPTER IX

CASE STUDY SIX: R.S.

R.S. is a 30 year old man who celebrated his 20th birthday two weeks before his motorcycle crash in September, 1984. At that time, he lived on a sailboat with his father and sister. He was single and two and a half months into a moulder's apprenticeship. He'd known that he would do this type of work since he was 11 years old working in a blacksmith's shop in England. He earned double what his friends did and he was respected for his intelligence. He partied on weekends and evenings. His first paychecks went to buying motorcycles, booze and drugs. He planned to move into his own place.

R.'s main form of transportation was a motorcycle. A friend of his had lost his license so R. took his motorcycle and dropped him at work in the city before going out to the suburbs where his apprenticeship was located. He returned to pick him up at the end of the day. On the evening of September 4, 1984 he picked up his friend but traffic was particularly heavy so he turned off the main road and proceeded via side streets. He had only gone a couple of blocks when he spotted a van entering the intersection he was already in. They collided and then the motorcycle jackknifed into the van. R. flew over the top and landed on the sidewalk. His passenger was thrown against R. and fell to the side of the bike. He suffered a broken ankle.

R. was taken to hospital where surgery was required to remove a ruptured spleen. He was conscious until surgery. He doesn't know if he slipped into a coma or whether it was induced but it lasted three and one half weeks. One arm curled up under his chin and his parents were told there was nothing the doctors could do about it. Each day they

stretched out his arm, encouraging the muscles to straighten. After the coma, he was in a semi-conscious state for one and a half weeks.

He was in the original hospital for six weeks, then transferred to another for two weeks. There he regained the ability to talk and eat. His sister brought him a hamburger and a milkshake. They tasted really good. He began walking just before he was transferred there but he forgot. When the nurse arrived to take him to therapy, he asked for a wheelchair. She had to remind him that he was able to walk on his own.

After discharge he was referred to a rehabilitation hospital. He started in November 1984, going three days per week. He used transportation system for people with disabilities. He participated in occupational therapy which seemed to be practical stuff. He learned basic arithmetic skills. It was like the knowledge was on the tip of his tongue but he couldn't quite remember until they refreshed his memory and then it was easy. He worked in the woodshop and made a wine rack for his parents for Christmas that year. He was part of a group who met to talk about what happened to them. It was run by a leader with firsthand knowledge of head injury. R. worked out in the gym to build the quadriceps muscles to support his knees. The muscles supporting his hands and knees were weak from sitting or lying down so much. He learned how to make cookies which he took home and ate. He proved to himself that he could cook, something he had never done before his crash. He found it easy to do the rehab program because he had a lot of acceptance. He had already recovered to the point that he was satisfied he was like most other human beings. He felt like a robot going to therapy. He went because he was told to go and he accepted that.

After a few months he was told to use the bus as part of his therapy program. He did that once and then went back to riding his motorcycle to the rehabilitation centre. He returned to work in March or April. He was given six months to determine whether he could return to his apprenticeship. Shortly before discharge in June 1985, R. got his motorcycle license back.

During his rehab R. lived at his mum's place. He was told it would be better for his balance than living on a rocking boat. In May 1985, his mother moved in with a good friend of his, the one who was in the crash with him. R. felt left out so he moved in with another friend for a month. That didn't work out so he went back to his father's boat. Over the next year and a half he went back and forth between his parent's homes. He felt pretty unstable, unsettled.

R. thought he was ready to return to apprenticeship but in the summer of 1985 his boss hired a new apprentice. He felt angry and discouraged because he was really trying to get back in the swing of things. He didn't know what to do. His girlfriend was going back to high school so he decided to go too. It didn't work out and the relationship deteriorated. He felt left out no matter where he was because he wasn't working. He rode his mountain bike across town to a friend's house and stayed there all day, riding back and forth for meals. He was lost and without direction in his life. His dad told him not to show the insurance company he was capable of working as well as he could before his injury. If he did, he court case wouldn't be worth anything. He didn't want to prove himself in a positive way and he found it easy to be lazy, almost addictive. R. fell back into partying and drinking.

His legal case settled in February, 1987. He received a cash settlement. His father advised him to save the money and work for a living. R. bought a house and got a job but found he was really sensitive to what other people did or said. He was temperamental and moody. He quit the job. He got another one and quit that too. He sold his house and bought another. He tried more jobs. He never got fired but often quit impulsively. He partied every night of the week and realized he was in a rut. He sold his house and moved to a different area seeking a change. The problem there was the exact opposite. He felt too isolated so he sold the house and moved back to familiar surroundings. Over the next seven or eight years he moved every 18 months. He bounced around, trying to settle down in life, trying to find a place in life but without any direction on how to do that. He knew what he wanted but he had no idea how to get it or what he was doing wrong. He wanted to get married and have a family, like most people do. He tried a few relationships but none of them seemed right for him. He wasn't having any success so he moved around, hoping that by changing his surroundings he'd find what he was looking for.

In 1990, he considered driving jobs so he completed a defensive driving course and received his class 5 driver's license. He bought himself a pick-up truck but the jobs didn't materialize. In 1993 he worked a few months in the summer but he got angry at something his boss said or did and he just walked out. Other jobs he tried ended the same way. He became really discouraged. He figured he could do the work alright but he was being more temperamental, more sensitive with what people said and things that happened. At one job he was promised a raise after three months but then he never

received it. He waited until payday and then quit. Before he would have fought for what he had but instead he got discouraged and just took it.

He saw a psychologist who was recommended to him after his settlement. He rode his bike over there a couple of times a week for support and direction. She suggested that he go the B.C. Head Injury Association and she also directed him to a psychologist who specialized in drug and alcohol addiction. He was given information on the effects of marijuana, how it makes you think. He was directed to an Narcotics Anonymous meeting. On February 11, 1994 he attended his first meeting and stopped smoking dope. At the meetings he heard how people's lives had been destroyed by their use of drugs. He didn't think his problem was that serious but he discovered plenty of reasons to stay away from it. He hasn't touched it since.

In the autumn of that year, he contacted the B.C. Head Injury Association and was directed to the John Simpson Centre, a social and activity centre for survivors of TBI. He got involved in activities such as bowling, going to water slides, having lunches and dinners there and meeting other people who had also experienced a brain injury. R. discovered he was the only one driving to the Centre. He arrived on his latest motorcycle. He felt like he was in his own class of recovery. He saw himself to be an inspiration to other members because he'd come along further than most others. They shared personal experiences and worked through problems together. R. felt good about himself compared with most other people. He found himself analyzing the people there. By comparison, he perceived himself to have a better attitude and to be less self-centred than most of the them.

It was at the John Simpson Centre that he met S. She was having problems with her boyfriend. They had coffee together and talked. He was kind of shy but he got his nerve up and invited her to a rock concert in December 1994. He had rushed out to buy tickets for the Rolling Stones. He had butterflies in his stomach when he approached her but she was thrilled and he was thrilled. It was a very exciting moment for him. They began dating after that. On February 11, 1995, exactly one year drug-free, he proposed to her. He had asked her dad's permission the day before and was welcomed into the family. She accepted his proposal. He felt like this was his reward for giving up his partying lifestyle.

But everything happened too fast. They went to jewellers, picked a church and reception hall and sent out invitations. R. freaked out because he couldn't grasp how things were going along so fast. People don't usually meet each other and get married in the first half year and here it was three months later and everything was arranged. It didn't seem normal. He considered himself to be average, normal, his injury undetectable. Things didn't seem right and they fought a lot. They agreed to postpone the wedding and give themselves more time. They decided to wait until March 1996.

Upon reflection, R. thinks some of his difficulties with work stemmed from his settlement with the insurance company. He received a big lump sum which he invested. As a result, he had a monthly income so he didn't have to work like most people. He wonders if this accounts for his being more temperamental at the jobs he tried. He also felt compelled not to work before the settlement because if, for instance, he had successfully returned to his apprenticeship and completed it, what would his court case

worth have been worth? So before the settlement, he didn't try that hard and after the settlement he had the luxury of not needing to work, so he was more temperamental at the jobs he did try. "It would be great I guess if someone did research and had insight that would help people in the active stages of their recovery and help them get a direction or a sense of things". This was something he didn't receive. R. recalls getting bits of information from family or friends but not enough to get a clear sense of direction, a plan for how to proceed. At the time he wasn't aware of what was missing or what he needed. He didn't realize his own role in his difficulties, his lifestyle and his expectations. Even in the summer of 1994, before meeting S., he drove his motorcycle around the province looking for a new place to live, convinced that if he changed his environment, things would work out.

R. considers other people he knows and wonders why his recovery is so much better than theirs. It doesn't seem fair. He thinks one factor in his success is positive thinking. He tries to move in a positive direction by setting goals, going to the gym, and trying to eat better. He has positive expectations for the future and he holds onto them, no matter how moody he gets. He gets out of negative thinking by recalling a past memory that makes him smile or laugh. Another technique is to look for the positive side of a negative situation. Maybe he can draw something good out of what is happening. He's found that since his injury, he's gets pleasure from helping other people. He doesn't have a lot of schooling but wonders if he could be a benefit to a group or organization by helping people with TBI through some of the tough times, assuring them there is a light at the end of the tunnel. Each person is different and each

injury is unique but he's thinks there are some people out there whom he could help regain a sense of optimism and independence.

He has cut back on his drinking and is feeling better for it. He's moved away from the numbing effect of drugs and alcohol so that he can accomplish more. He also has full use of the arm that was paralysed after his injury. He believes his parents interventions made the difference. In addition, he believes he has mastered what he considers the common traps of people with TBI, self-centredness and denial. He is aware of his limitations and the tendency of someone with TBI to be impatient. He refers to occasional stuttering and points out that if he slows down and puts his thoughts together first, he's fine.

R. anticipates difficulties will persist in a couple of areas. Managing his anger is one of the challenges that remain for him. He can tolerate a lot but then some little thing will get him really frustrated. He can analyze the problem in the past tense but when its in the present, his anger erupts. Cognitively, his concentration is not as good as it used to be. He believes the studying required to complete an apprenticeship would be too much for him.

He looks back on the last 11 years of his life as a learning experience. He sees ways in which he has evolved in steps or stages as most people do. He sees a natural progression from eating junk food and partying in his late teens and early twenties to eating better and moving away from drugs and alcohol in his late twenties. He thinks of friends who have gone the same way and some who never evolved and ended up dying young.

In recovery, most of the improvement comes in the beginning and then gets more and more gradual until eventually one doesn't even notice the improvements. He believes his final goal is to get a job and be stable with it, to last more than three or four months. He hopes to find a position where he can do his job, do some things with his co-workers like playing baseball, and go on average person's vacations. This is something he has dreamed of but never done. If he can do that, he'll feel like he's made it. He believes that if he can meet that goal, he can finish with recovery and just have goals in life instead of steps in recovery. He wonders if this might have happened sooner if he'd had some guidance earlier in his recovery. He thinks it would have been helpful to be able to get advice and some direction. He wishes there had been someone to lead without pushing or setting big expectations. Maybe he wouldn't have felt so lost and disconnected. Perhaps he wouldn't have struggled for so long to get what he wanted and needed in his life.

He just moved into his fifth house. He's settling down. Meeting S. has been a positive thing in his life. She is supportive and offers good advice. She taught him to follow a budget and keep receipts. Now he has a filing cabinet to keep all his records. All his goals have been reached except for work. He considers the possibility that he could go to a new job, get pissed off after a short time and face the need to do further work in recovery. Its hard to tell because he's never sat down with a professional and reviewed his life, to determine where he is and what remains to do. He's doesn't know what's left to achieve in recovery. "I've got no direction in recovery now. My life has direction, my recovery doesn't".

COMMENTARY

Large segments of time and numerous events were lost following R.'s crash. He was told that two large paramedics were required to hold him down at the scene because he was fighting them with all his strength. When he came out of the coma things were hazy but he knows he had to re-learn basic living skills. As he became more active, he concentrated on his physical health and was not aware of the impact of the brain injury. His goal was to return to normal physical functioning, meaning to walk and talk like everyone else. By the time R. left hospital, he felt normal.

It was hard to understand why he had to go to the rehab centre but his dad said it was the best one around so he did as he was told. For the most part, he complied with the demands of a rehabilitation program but he didn't really think he needed or benefitted from it. When he was told to take the bus there he saw no reason not to ride his own motorcycle so that's what he did.

R. returned to the life he was leading before his crash. He met with his friends who partied with drugs and alcohol. This was familiar territory and little had changed. He returned to his job but was advised not to be too successful because of his settlement. Even so, losing his apprenticeship was a real shock. It didn't make sense. As far as he was concerned, he was quite capable of doing the work.

Leaving his mother's house marked the beginning of wandering and restlessness. He moved from place to place never finding what he was looking for. His cash settlement offered financial security but it also reduced his motivation to find and keep a job since he had an income regardless. He thought moving away from his partying

friends might help him start a new lifestyle but he instead discovered he was cut off and lonely. Later, when he wanted to work, he encountered unexpected problems that undermined his goal. He repeatedly quit jobs because of his anger, frustration, and impatience. He felt unstable and directionless. He had expected to have a trade, a place of his own and a relationship but he had none of those things and no idea how to get them.

Nine and a half years after his accident, R. took the advice of his therapist and spoke with a drug addiction counsellor and attended a meeting for drug and alcohol addiction. He learned how they were affecting his life and his brain and he decided to make some changes. He gave up drugs and started attending a drop-in centre for people with TBI. He felt proud arriving there on his motorcycle. It represented a level of recovery and independence that many of the other people didn't have. He began to see himself as a role model to them.

Another turning point was meeting S. He felt great when she accepted his invitation for a date but he truly believed his life was changing for the better when she accepted his marriage proposal. One of his dreams, to get married and have a family, was being realized. He had found some of the direction in his life.

Life was going quite smoothly by the end of R.'s story. He was looking forward to getting married and settling into a new lifestyle with a partner. He was on good terms with his family. The biggest question that remained for him was whether he could maintain a steady job. He came to understand that he could not complete an apprenticeship because of the studying that was required. It would have been too much

for him then and now. He also decided that the problems he encountered on the job were caused by his impulsiveness and frustration. He wondered if he could manage his anger well enough to work through the problems. He wanted to be able to be a reliable worker and get along with others, both on the job and socially.

In hindsight, R. considered his rehabilitation to be too much at the beginning and not enough later on. He went because he was told to, not because he believed he needed to. After his settlement, when he was struggling with jobs and wanted a sense of direction, he didn't get the rehab that he wanted or needed. He got advise, directions, manipulation, and lectures from his family and friends. At work he was temperamental and defensive with co-workers and bosses. He flew off the handle and quit impulsively.

By the end of his story, however, he was feeling pretty good about himself. He had matured and taken responsibility for his use of drugs and alcohol. He made exercise a priority and watched what he ate. He was a christian and proud of it. He beliefs and his acceptance of himself guided his involvement with his partner, and the social centre, and with his family. A lot of things seemed to have slipped into place and his life had gained some direction. The one remaining test was employment. The second priority was to take a holiday, perhaps to fly his future wife back to England. He looked forward to those new and normal experiences.

CHAPTER X

CASE STUDY SEVEN: S.C.

S. is a 40 year-old woman, divorced, with one 13 year-old son, W. S. earned a degree in Home Economics in 1977 from UBC and received her teaching certificate in 1978. She taught home economics and law at a private girl's school for four years. While on maternity leave, her contract at the school was terminated. It was a difficult time because her husband needed surgery and so they were both unemployed. Then he became involved in a cult-like organization and his behaviour changed. He became very strange. He walked out, leaving S. with a ten month old baby. She didn't know what to do or how to support her son.

A few people suggested that since she didn't want to be separated from her son, she should start a daycare. At first she thought they were being facetious and rude. She wasn't even sure what a daycare involved but decided it was worth investigating the idea. She went through the health department to meet the requirements, got her license, and opened a daycare. Instead of the 120 students she taught at school, now she was dealing with seven children and seven families. It was wonderful. She carefully selected children whose parents were interested in the same activities and programs that she was doing with her son. As well as learning activities, swimming, skating, and going to parks and playgrounds with the children, the families participated in picnics and barbecues. They took camping trips together in the summer. It was like a big extended family.

S.'s background in swim instructing and lifeguarding was invaluable for her

daycare activities. She also kept her first aid and CPR certificates up to date. Her background in law was helpful during her divorce which ended up going to Supreme Court in June 1984. She wrote out her demands and the lawyer used the document to get everything she asked for. She lost some of her friends through the divorce and so this lifestyle of daycare/extended family was great. It also provided her son with important socialization. Basically it was like having all the brothers and sisters he didn't get.

In 1985 allegations arose that W.'s father had sexually assaulted him. S. found a psychologist so that she and her son could work on healing from this trauma. W. made good progress over several years and S.'s ex-husband was eliminated from their lives.

When she wasn't running her daycare and organizing group outings, S. skied, swam, and skated. She considered herself an athlete. Professional development was also a priority for her so she attended workshops and conferences and was on the executive committees of the local and provincial daycare associations. She was active in passing a motion to make first aid certification a requirement for daycare operators, and promoting a proper meeting agenda which included guest speakers. She contributed information regarding business, disability and liability insurance coverage for daycare operators.

Life was going well. She was supporting herself and her son. She was watching her son grow up and enjoying activities and relationships she built with the other children and their families. Her goal was to continue this way until her son entered high school. Some teacher friends had asked her when she would return to teaching. She told them that what she was doing was so easy and such a nice lifestyle that, at that point in time, she wouldn't consider going back to a rat race of 120 kids every day. The thought of all

the testing, all that marking and all those stupid staff meetings didn't appeal. She'd have to be crazy. Once W. was old enough, she thought she might return to university to get a Master's degree. She hadn't yet decided what she would study, but she thought psychology was a possibility. She learned a lot from the psychologist who treated her and her son and she believed that she had grown and strengthened as a result of the experience.

On July 27, 1991 S. was driving to the bank to get money for their summer holidays which were to start in four days. She was in the left lane and stopped behind a car which was turning left into a cemetery. There was traffic coming so she had to wait and then, at the exact moment when the car in front turned, she heard a huge screech of tires and the bang as she was hit from behind. Her head yo-yoed against the head rest and the car was pushed past the gates of the cemetery. She just sat there. She knew she needed to get the car off the road but she couldn't figure out what to do. Her son kept telling her to pull into the cemetery but she couldn't respond. After a long time and when there were absolutely no cars coming, she manoeuvred the car across the road into the cemetery.

The driver who had hit them wanted to call an ambulance. S.'s hands were shaking so badly that she sat on them so her son, nine years old at the time, wouldn't see them and become frightened. She had him take her license out of her purse and copy down the information. He showed it to her but her vision had narrowed right down and it was like looking through a microscope. He got the numbers reversed but the other driver corrected the errors. After a while she tried driving around the cemetery. She

kept bumping into curbs. She decided to drive to her mother's house, not far away. It took a long time to turn back onto the main street because her perception of distance was off and she was very slow to react. As she was driving, she was suddenly hit with a burst of nausea, sure she was going to throw up. She managed to turn into a park and stop. Their dog was in the car with them and was hyper. S. knew she needed to get the dog out of the car. She also realized she wasn't going to be able to make it to her parent's house. She instructed her son to ask some women passing by to help her by calling her parents. They also called the automobile association because smoke was pouring out from under the hood of her car. From that point on, she doesn't remember anything except the sensation of being in her parent's home, knowing she was safe. She was taken to emergency but doesn't recall this happening. Apparently she was checked over and released. She was in shock and confused.

She called one of the parents from her daycare who instructed her to close the daycare and begin her holidays immediately. Over the next two weeks, she refunded their money and tried to find a daycare substitute. At home, lying on the new beach towels she was supposed to take on her holiday, S. slept a great deal and had her son put ice on her back three times a day to manage the pain.

Problems began immediately following the accident. When S. saw her doctor she became very emotional. Her doctor told her that she was suffering from anxiety and stress and that she should rest. She hired substitutes for as long as she thought the parents would tolerate it. Even that was problematic because she called for recommendations and was told that she had already made the request and been given

names. She was confused. Later she came across the list and it was like an electric shock response. She couldn't remember what she had done. She tried to staple important papers together but then she lost them. She started piling them on her bed so they'd be right there beside her. Soon she ran out of space and started piling them on the floor. They were all important papers so she didn't want to lose them.

She returned to her daycare responsibilities but it was all she could do to stay awake until 4:30 when the children left. Sometimes her son had to shake her off the couch. She'd lie down with the children at nap time and then couldn't get conscious enough to actually get up. She could hear them playing and knew they were alright but she couldn't rouse herself. She found it difficult to keep track of activities. She'd forget snack time or even lunchtime until some of the children complained they were hungry. She couldn't prepare soup for them unless they were all settled and quiet, not needing supervision so that she could be alone in the kitchen, standing in front of the stove the entire time. Otherwise, she'd forget it was on the stove and it would boil over and burn. She couldn't even make meals at the end of the day. It took her until like nine or ten o'clock before she even got a meal ready. She kept burning spaghetti on the stove and the smoke detector would go off and she wouldn't be able to figure out what that damn noise was. W. would laugh and tell her it was the smoke detector, stunned that she didn't know. After burning the spaghetti, she would just re-do it and then burn it again and then re-do it and burn it again and re-do it and would finally decide to get take-out. They ended up ordering in a lot of food. Even with the microwave oven she had problems. She completely forgot putting anything in it. It would beep when it was done

but if she didn't get it out immediately, she'd find mouldy food on some other occasion when she went to use it again. She got dizzy bending over the dishwasher. She couldn't recall where the dishes went in her cupboards.

Her sense of balance was off. Walking on flat ground felt like the sensation of having a movie camera on wheels and having everything rushing at her too quickly. She could no longer ski or skate. The pounds started accumulating on her previously athletic frame. She lost any sense of hunger and would only think to eat if she passed through the kitchen and saw food. When she did sit down to eat, such as in a restaurant, she found she couldn't stop. She was terribly embarrassed by this behaviour.

She thought she must have damaged her eyes because her perception was so badly skewed. She tried not to drive at night because she couldn't see properly. Her eyes would go off the road and get glued on the sidewalk even though her head would be facing straight ahead. She knew she was supposed to be looking in front of her when she was driving. She noticed that her eyes would just go to the right, they wouldn't go left. She couldn't even pull over at that point because she couldn't see what was in front of her, if there was a parked car in her way. It didn't happen all the time, just once in a while. It was intermittent and unpredictable.

Anything with left and right was also confusing. She drove familiar routes but turned, for example, left instead of right, convinced she was going in the correct direction when she wasn't. Similarly, she consistently got mixed up with the knobs on the showerhead. She was burning herself all the time in the shower. She tried to remember to turn the shower on first before she got into it and then to hop out before she

turned it off. It was hard so she stopped taking showers for a while. Then she forgot about them. She just put on deodorant and washed under her arms. Washing her hair was another trial. On one occasion she washed her hair six times in a row before she realized and said to herself, "stop, you've already done this". It was like over and over and over again and not being aware of what she was doing. It was only when she finished her pre-measured bottle of shampoo that she realized what she'd done. She had very shiny hair but she couldn't look at herself in the mirror because it was like there was nobody there. "When you look at your own eyes in the mirror, there was no sense of me at all".

She also became really concerned about her outbursts of anger. While on a trip with some of her clients, she confronted a campground worker over unfair entry practices. She was so angry that the manager threatened to evict her. Camping became stressful because she couldn't remember from one minute to the next where her son said he had gone. She kept going to the field to check on him and he'd complain. She couldn't relax, constantly looking around, wondering if there were wild animals in the area, cougars and bears. They had to come back early from the holiday because S. found she couldn't tolerate lying on an air mattress for more than three days due to her back pain.

S. also had great difficulty when it came to reading. Her eyes wants to go down the page, not across it. When she told that to people, they made jokes about taking up chinese. S. found she could read the words on the page if she put her finger underneath the line. Then she could read relatively quickly but she had no idea what the document

said. The ophthalmologist couldn't find anything wrong with her eyes. He cracked a joke as well and she was outraged at his behaviour. S. felt like she was surrounded by dinosaurs and incompetents. She concluded that she needed to find somebody else who was up-to-date on how to talk to people and how assess the problems. She described her symptoms to her doctor, but she found it hard not to cry, and he told her she was flipped out over her injuries and suffering stress and anxiety. He said she needed to rest. She couldn't accept this diagnosis since she loved her work and apart from that commitment, she had rested extensively since her accident.

S. was investigated by the Health Department regarding her daycare. They told her they'd had a complaint issued against her and were coming down to investigate the daycare. She was in a panic and called a girlfriend to come with her because she couldn't talk, she was going in circles all over the place. Her friend reminded her to breathe and helped calm her down. S. knew the incident in question. She had taken four children to the local pool to look at registration for swimming lessons. As they were leaving, they passed a baseball field where some seniors were hitting the ball every which way. It was a try out for a seniors team. Suddenly, one of the balls came up, looped over and almost landed on the head of one of her two year olds. She was sure it would have killed him from the height and angle that it came down. She went berserk. She stood right in front of all of these people, as if it was an open stage, and she yelled and screamed and ranted and raved. She went storming back into the centre to find out why these people were allowed to be at risk of injuring themselves as well as others. The person that was supposed to be in charge of that field was on holidays and the person

covering her wasn't even aware there was anybody on the field. She said their insurance wouldn't even have covered them if there had been an accident. The woman thanked her for drawing it to her attention and she was very calming. S. and the children headed back to the car but she was still really upset. Her whole body was shaking. They passed by some bushes that had red berries and she noticed that one of the kids had something in his mouth. He was moving his mouth funny and she thought that he might have gotten some of these berries. She thought one of her kids was going to get poisoned after another almost got killed by a baseball. Then she became aware of a tennis player who was watching her. He stopped by a tree and she felt like telling him to just f___ off. He watched her trying to get whatever it was out of this kid's mouth. She was so agitated she didn't even notice if she found anything. They went back to the car and she realized she was not in any shape to drive right then. She decided they would have snack time right there, between the two cars, on the curb. She got out some peanut butter and crackers. She always kept some in the car because she never knew when she'd forget to bring snacks with her. She was buttering with the knife when one of the children asked her why she was so upset about the ball. She said, "because he could have been killed!". The tennis guy came straight over and told her she shouldn't be working with kids. He told her she had a big problem, talking about killing children. Despite his hearing only part of what was said, she realized it didn't look good, particularly with her standing there holding a knife. She could understand his concern so she explained that she operated her own daycare and told him what had happened with the baseball. He said she was exaggerating the situation, that it wasn't that serious, that baseballs rarely kill

people. She pointed out that he was not responsible for these children, she was and that he didn't care about them like she did. He wanted to lodge a complaint so she gave him the name of the person to call at the health department. She thought this would be preferable to having him call the police right then and there.

So the inspector came and they talked about it and she too thought that S. was a little stressed in this particular situation and maybe she needed to go and talk to somebody. She sent S. to the Mental Health centre to talk to a registered nurse. She saw the nurse once or twice and told her all the symptoms she was experiencing. S. explained that her doctor was not sending her anywhere. Some people had suggested she see a neurologist but she didn't even know what a neurologist was. The nurse advised her to give the doctor an ultimatum. He either sent her where she wanted go or she would find another doctor. So that's what she did.

What she got, instead, was a referral to a psychiatrist. When she discovered he was at psychiatric hospital she was convinced that she was being intimidated. She was really upset at the thought of even going up there. She believed she was being written off as a basket case. To her surprise, she found him to be one of the most highly scientific people that she'd ever met in the medical community. She was so pleased that she asked him to handle her case from that point on. S. didn't want to have anything further to do with her physician. She explained the problems that she was having. The psychiatrist said he would check out the physiological symptoms first, before the psychological. This approach was a great relief to S. because she was sure her own doctor was chalking everything up to her being female. She couldn't believe she was

suffering from stress and anxiety. She'd been operating a business for nine years and finding it a breeze. She had coped with her husband walking out, she was making her own money in her own business, and she was actively involved in her son's development.

The psychiatrist explained that he would have to wait for her physician to turn everything over to him if he was going to proceed with it. Her physician refused, explaining that he was handling the case. So he sent her to a neurologist who did a three page assessment. S. was really appalled. She gave him so much information and what he produced seemed so minimal. In early 1993, she and a friend went over the reports. As far as she could tell, they stated that nothing further would be done before the litigation proceedings. S. decided that if they were not going to do anything, she would have to figure out what to do. No one was coming through with any answers and she was really beginning to doubt herself.

Since her trial was approaching in June 1993, her lawyer asked her to review the medical reports for accuracy. She spent hours and hours reviewing reports with the help of her friend. In a 17-page letter, she refuted much of what had been written by her physician. When he saw her corrections, he was furious. He accused her of not trusting his judgement and told her that after the trial she would have to get a new doctor. He suggested that her anger was not at his report, it was transferred from her anger at her ex-husband. She couldn't understand why he was bringing up all this old stuff. She wasn't angry, she was simply trying to be accurate. She had made such corrections to all the reports she had seen, not just her physician's.

She decided to phone the psychologist she had worked with over the sexual abuse

allegations. S. figured this was the only other person who knew her well, over several years, and might have some insights into what was bothering her. S. asked about personality testing because she wondered if she was cracking up. Maybe she'd just had fun for too long. S. explained her symptoms and the psychologist referred her to the College of Psychologists for names of neuropsychologists. The neuropsychologist explained about the testing and warned her that it might not show anything specific but would provide insights into her strengths and weaknesses in different types of memory. She believed that any information would be helpful so in the spring of 1993 she went ahead with it and paid for the report herself. The report stated that her visual memory was in the 90th percentile and her auditory memory in the 30th percentile. She'd hear what people were saying but if she didn't write it down immediately, it was gone. It was almost like being deaf. The final diagnosis was mild head injury.

S. felt immense relief because at last there was some explanation for the problems she had been experiencing. It wasn't just a female nervous breakdown. She had felt like she was going crazy and now she knew she wasn't. She began to understand how visual and auditory memory differed and how she might use this information to adjust daily living activities. The neuropsychologist also directed her to the B.C. Head Injury Association and to a psychologist who worked with people with head injuries.

S.'s physician and lawyer were intensely angry when she produced the report with its diagnosis of mild head injury. She was surprised and dismayed by their reactions. Her case was to go to trial in June 1993. They sought an adjournment but it was rejected. It was postponed after S.'s father suffered a heart attack just before the trial. It

was re-scheduled for October 1994. At the end of 1993, the insurance company agreed to fund an occupational therapist for S. She also found a new physician.

The occupational therapist found S.'s bedroom covered in paper. S. didn't see a problem with it. She put the most important papers on her bed and the next most important on the floor near her bed. She didn't want anything moved because this was how she knew where things were. She didn't see that her entire room was four feet high in paper, little apartment buildings and skyscrapers going up around her bed. They started work on S.'s cognitive problems. The OT helped her set up a dayplanner to keep track of her commitments. Since her communications, both spoken and written, often missed the point, they came up with a technique for telephone conversations. She learned to prepare how, what, when, where, and why questions before she called. Harder still was making herself clear in business or rehabilitation-related correspondence. The OT also suggested labelling the kitchen cupboards but with parents coming and going, S. didn't want them to see that she couldn't remember where the dishes went. She used this technique in the privacy of her own bedroom.

In August 1994, she flew to California to consult another neuropsychologist. S. paid for a friend to accompany her so she could get S. to the right place, on the right day, at the right time. The idea of that really made her angry because it seemed like anywhere she wanted to travel with her kid, she had to go with somebody else because she didn't know whether she would be able to problem-solve in situations, particularly if she got angry. She felt like she was just tagging along, not allowed to do the things she wanted to do.

S.'s trial was postponed by the insurance company until March 1996. At the end of June 1995 there was discussion regarding how she was going to continue to finance her rehabilitation. She had been given a ten thousand dollar advance from the insurance company in November 1994, to continue having the occupational therapist work with her. When she asked her lawyer about more funding to continue the rehab, she was told there was no financing for her. She had asked if she could hire a rehab specialist, a case manager to streamline medical and legal issues. They said no, not even if she paid him herself. Her lawyers also admitted to her that they failed to open the part seven coverage which covered rehabilitation expenses. They claimed their liability insurance would cover them. She had the neuropsychologist's report in May of '93 diagnosing mild head injury so they should have opened up that section in June. The two year window to do so ended in July 1993.

Although she had trouble thinking in sequence, given time she could still think and problem-solve and it seemed to her like they were involved in a conflict of interest. S. decided to find a new lawyer. She consulted with one who confirmed that there was a conflict of interest and advised her to change lawyers. The people at the Head Injury Association encouraged her to get the right lawyer for the job, not a divorce lawyer but one specializing in head injury cases. She started interviewing lawyers who had been recommended. She needed to find the right one to prepare her case for March 1996.

S. believes that doctors got the impressions she was upset all the time because she found it hard to talk about her problems without becoming emotional. She wasn't sad all the time. Mostly, she was just trying to get on with living her life. Her sense of humour

helped her cope. One strategy she used was to find something positive to balance each of the negatives she encounters.

She uses a computer to organize her affairs. With it she can write out all the steps for her daycare so she's less likely to forget some of them. She still takes hours to write a one-page letter but after taking a creative writing course, she discovered that she can write about the first 36 years of her life with perfect sequencing. The linear thinking that is so difficult in the present is not problematic when using her long-term memory to describe the past. She finds that this kind of writing, over which she can become quite obsessive, hooks her back into feeling normal. She has received praise and encouragement for her work.

She's horrified when she reflects back on incidents such as the camping trip and thinks, "wow, this is not the way I would have normally handled anything, ever!". With her training as a teacher and having dealt with so many different kinds of parents, she's always been able to be cool, calm, and politically correct. To have lost control when she was on a camping holiday, not under any stress at all, made it all the more shocking to her. She was there to relax and have a good time, but instead she went off the deep end. She realized in hindsight that her son was totally embarrassed by her behaviour. She learned to manage her anger better. She and her son worked out a joint plan for when she becomes too angry.

She feels a great deal of regret that she missed much of W.'s growing up over the past four years. Birthday parties were missed and at times she was unaware of his presence. She arranged her career around her son but since her accident that seemed to

slip out of control.

She's also horrified when she reflects on her lack of awareness of problems. She taught her children to wrap her sprained wrist. She considered it good learning for them but didn't realize she did it because she couldn't remember how to do it herself. She feels like crying when she thinks of these events.

By contrast, she was told many times, and continues to be told, that she overreacts to situations. For instance, if she thinks a child may be drowning, the intensity of her experience is said to be out of whack. It's hard to understand how they can be so nonchalant and expect her to be likewise. Still, she knows that she used to be less focused on other people and more diplomatic in her approach to them. Now she's abrupt and demanding, almost aggressive in her stance. She's not too friendly any more.

S. made the decision to close her daycare in November 1995 and concentrate exclusively on her rehabilitation for six months, even if she had to pay for it herself. She knew the parents would be upset with her but she couldn't stomach the ethical dilemmas any more. There had been dangerous situations and she couldn't wait for an accident to happen. S. wanted to get herself organized and figure out what she can do career-wise. She knew there were opportunities for her and she was determined to find them. She wanted to be able to bump into an acquaintance, talk for five minutes, and then remember to carry on with whatever she had been doing before. She wanted to be able to speak to someone without losing awareness of other people in the room. She wanted to identify her strengths and concentrate on them. This may mean working with other people who can do the tasks she struggles with. She knew she could overcome the

problems and find new ways to support herself and her son.

She can look at herself in the mirror now so she believes she must have attained some acceptance. It is not the same person that she sees there but she can look to the future and anticipate making the changes necessary to feel good about herself again. She can face herself again. She knows what the goals are now and she can see what the problems are. "Awareness is really necessary before you can begin any kind of change".

COMMENTARY

From the moment she was struck by the vehicle, S.'s experienced disorientation and confusion. She couldn't gather her thoughts and it took a long time to be able to manoeuvre her car to a safe place. When she was in the safety of her parents' care, she could not remember events, such as the trip to the emergency ward. As time passed, she discovered that she couldn't remember how to get to familiar locations. While en route she also forgot why she was going to a particular place.

S. needed to find substitutes for her daycare children while she was recuperating. She called the association to get recommendations and they told her she had already spoken to them. She had no recollection of doing this. She washed her hair only to discover that she had emptied a pre-measured bottle. She would have had to wash her hair six times to use that much shampoo but she could only recall doing it once. Another thing that didn't fit was her doctor's diagnosis of her problem. He was convinced that she was under great stress and needing rest. She had spent her holidays on her back and slept every chance she got. She loved running the daycare so that didn't explain it. She was sure there was something more to it.

Since there was said to be nothing wrong with her, S. stepped back into her role as mother, daycare operator, and so on. She just wanted things to get back to the way they were before the crash. This proved to be tougher than she expected. She had trouble setting and following a curriculum for the children. She had trouble staying awake. She greeted the parents in the morning and evening but discouraged any further contact. She didn't devote as much time to her son. She tried to be the same as she was before, but it wasn't working.

S. found a variety of ways to cope. She started with daycare substitutes, she assigned tasks to the children (such as remembering one item each on the grocery list) to cover her memory lapses, and she had them remind her where they were going by turning it into a game. She put post-it notes on her steering wheel, to remind her of right and left, and of where she was going and why. She learned to settle the children so they didn't need supervision while she made their lunch. Otherwise, she couldn't do it.

S.'s biggest challenge with rehabilitation was obtaining it in the first place. Because her injury was undiagnosed, she had to approach her own psychologist and then pay for her own neuropsychological assessment before anything happened. It took over two years before an occupational therapist was provided to her. She sought information that led to her to the local head injury association before she found a psychologist familiar with the sequelae of brain injury. Once she had access to some rehabilitation she found it generally positive and useful. It was difficult adjusting to some of the strategies they advocated, such as putting labels on her cupboards. Initially she was surprised at the OT's reaction to her bedroom. She hadn't noticed anything wrong with her habit of

keeping important paperwork on her bed. The psychologist helped her understand herself better. They discussed ways to better manage the problems she was encountering on a daily basis. It helped to work on her anger, her intense feelings, and her confusion over why she was feeling that way.

Despite her efforts, S.'s roles changed. In the early stages she was unable to interact with the parents of her daycare children. Later, when she became re-involved in outings and camping trips with them, she wasn't in control as she had been in the past. Things changed with her son. He had to assume responsibility for some of the things she was incapable of doing. At times she wasn't even aware of his presence, whereas on camping trips she became hyper-vigilant of him, extremely worried about his safety. S. perceived herself to be an intelligent, independent, and controlled person but she lost her confidence when dealing with doctors and lawyers. She found herself becoming unusually emotional with them. She felt inadequate and helpless. She went to see a specialist, prepared to repeat her entire story. He just wanted her to list her symptoms. She had to try and think of them but each time she tried to balance a negative with something positive she could do about it. She cried because she felt so out of control. No matter how much she tried to see a positive side, the problems were out of control. Whenever she felt that way she noticed other people's expressions. It created an intense feeling of being judged as different, really different. It hit her like she was being run over. With her friends she found herself in a new position of dependency. When it came to travelling or reviewing reports, she had to rely on a friend to help her. Finally, her own sense of herself had changed. It was hard to play old roles when she wasn't

sure who she was. She couldn't see herself in the mirror and she couldn't predict or trust her own abilities. She felt like a stranger to herself.

As she tried to carry on with her life, countless incidents challenged her perceptions. At the time of the accident, she was unable to follow the standard procedure of exchanging license and registration information with the other driver. As time passed she discovered she frequently burned herself in the shower because she couldn't recall which handles were hot and cold. She realized that she washed her hair six times. She got lost at the San Diego zoo and couldn't remember the name of the hotel where she was staying. She couldn't recall where to put her clean dishes. She found old food forgotten in the microwave. She drove to the store and forgot why.

S. had changed careers because of the importance to her of raising her son herself. After her accident, she didn't have the energy or the motivation to even arrange a birthday party for him. Some years it was completely forgotten.

She was proud of her daycare, of the high quality of learning and activities she offered the children. By the fall of 1991, she couldn't stay awake for the whole day. She wasn't able to construct a lesson plan. She tried to pay attention but she wasn't sure she was alert to all of the risks. One two year old child came out of the bathroom coughing and spitting with foam around her mouth. S. tried to get the five year olds to tell what had happened. Finally she determined that the youngster had brushed her teeth with hair gel instead of toothpaste. She called the poison control centre to find out what to do. S. had a lot of training in CPR and first aid but she couldn't think, she panicked.

S. was stunned when she discovered that, all of a sudden, she looked different.

She couldn't look at herself in the mirror because it was just too devastating. She couldn't get her appearance looking the way she normally looked. It was like there was something missing, a major part of her was missing. It was like seeing an empty shell. She had no sense of herself.

When S. was investigated by the health department following her confrontation with the tennis player, she knew she was struggling but she also believed she had acted in the childrens' best interests. She welcomed the opportunity to give her side of the story and appreciated the suggestions and advice of the nurse she spoke to. This incident lead to her requesting a referral to a neurologist and ending up with a referral to a psychiatrist. He was the first person to recommend investigation of physical problems before assuming psychological ones. Later, when she thought she was going crazy, and contacted her psychologist, she ended up participating in a neuropsychological assessment. The results of that assessment indicated an organic basis for her difficulties. The diagnosis of mild traumatic brain injury was a relief and a turning point for S. She was directed to a local association for support and referrals and she was able to begin seeking out professionals expert in dealing with brain injury. It also provided validation for her claims. She was eligible to acquire funding for appropriate treatment. At that point she gained a sense of a direction she could follow.

S. also signed up for a creative writing course which opened new doors for her. She discovered that she had no difficulty recalling events in the first 36 years of her life. Writing about some of her experiences offered her new insights and most importantly, it hooked her into feeling normal again. This was something that she could do.

By the end of four years, the friction in her life was less intense but persistent. Her self-awareness had increased and was more accurate. Much of this evolved from gaining understanding of her injury, validation of her experiences, and identification of ways to cope. Even so, there were many times when she received incongruent feedback. At the pool she thought a child was drowning. S. started yelling. The lifeguard and spectators thought she was overreacting and she couldn't understand their lack of concern. When she finally found a lawyer who believed her and would take her case, he held out his hand to shake hers but instead she grabbed him and hugged him. Quietly, he instructed her to stop and when she stepped back and saw her friend's expression, she burst into tears. It had seemed like the right thing to do but she could tell that others didn't feel the same way. Later her friend told her it was inappropriate and embarrassing. She told S. that you don't hug lawyers, they are the last people on earth that you hug. Incidents like those remained baffling for S.

S.'s relationships were not as they had been prior to her crash. She didn't want the parents to know how she struggled to carry on with her responsibilities. She had to hide from them the mistakes she made, like when she left one of the children in the van. S. continued needing the assistance of her friends and her son. Her friend gave her feedback on her social behaviour so she could adjust it accordingly.

Prior to her accident, S. attended a motivational lecture. The speaker advocated the notion that no problem was too big too overcome. S. found it useful to apply that approach during her recovery. She saw on-going problems but felt optimistic that she could deal with them and move on. Earlier on that had been hard to do. At times she

thought she was dying and believed that part of her did die. She also figured she would have committed suicide if she had not finally received some help. She still felt very frustrated at times, tired of needing so much assistance.

Apart from her daycare, S. was active in her professional association, she pursued continuing education, and she combined athletic interests with social events with friends and her son. All of that was lost after her injury and little returned. She was trying to get back into a regular swimming routine but some unpleasant arguments with lifeguards made it difficult to persevere. By the end of 1995 she wanted to close the daycare and put her energy into her rehabilitation program.

There were still a lot of unknowns for S. She found it hard to know what the future held. She had goals to become more independent, which included accepting and accommodating her limitations. She was convinced that there was a new career direction for her but she was unsure what form it would take. Settling her court case in March 1996 would bring her one step closer to getting on with the future.

CHAPTER XI

COMPARISON OF COMMON PATTERNS OF NARRATIVE ACCOUNTS

The purpose of comparing the narrative accounts was to determine whether there were themes which they shared and to discover if a common pattern of meaning existed within them. The analysis began with the investigation of each account. Significant events were identified and a word or phrase which described the experience was assigned to each one. For instance, in listening to their stories and later writing and reviewing the narrative accounts, in each separate case the word 'invalid' sprang to mind. SR's reaction to a million dollar settlement was that he'd been shown to be incapable and unsalvageable. RS was devastated not just by being replaced in his apprenticeship but by the fact that he was not even consulted. SP's family didn't bother to visit her and her sister used her to get into bars. JG could not convince his lifeskills worker to acknowledge his medical background and honour his request not to be labelled with the term 'brain damaged'. GS's friends stopped calling or visiting. IG was told to shape up or be locked in a group home. SC's doctor dismissed her complaints as neurotic. The fact that events which sparked a sense of invalidation occurred in each story lead to the formation of a theme by that name.

Early reports of erratic behaviour, personal confusion, lack of memory, feeling dazed and having lost time were placed under the thematic title, disorientation. Experiences in which the person's interactions with others changed for the worse were conceptualized as a theme of having a diminished role with others. For example, IG's

mother had to make sure her daughter ate, SC got her daycare kids to remember one item each for the shopping list, GS was scrutinized by supervisors and peers, and SR's friends apologized for his behaviour.

For every theme the researcher sought concrete references from the narratives. The themes were refined or abandoned as inclusion of further experiences confirmed or contradicted their validity. The themes are the result of a long and thorough process of distillation of the events of the stories. For instance, a preliminary version included a beginning theme entitled 'focus on disability'. Upon further review of the theme and incidents described within it, it seemed instead that it was a component of the theme of 'conflicting sense of reality'. The focus on disability was annoying for the individual for the very reason that he or she did not perceive it to be an issue at all. Thus the category was withdrawn to better reflect the true nature of the stories. Similarly, a theme referred to as 'alarming realization of self-limits' seemed relevant for some of the individuals but when considered in light of all of the stories it appeared to be part of a prevailing experience of 'frustration'. This included alarming realizations plus many other experiences which were less dramatic in nature or that had a more gradual and subtle impact. All of these events contained the common ingredient of frustration at being unable to do something. The intensity of their emotional reaction left each person with a memorable imprint of the event and its consequences.

The name of each theme was evaluated and re-evaluated in light of the stories to ensure it was accurate in fact and in nuance. At one point the theme which is entitled 'reasserting personal agency' was called 'self-empowered acts'. Many of the events

which lead to the creation of this theme were self-empowered acts but the accomplishments that were described were products both of the act and of personal decision-making and determination. 'Reasserting personal agency' seemed to better describe the role of initiative that lead to the self-empowered act.

The pattern of recovery followed the storyline of a beginning, middle, and end. The themes of the beginning were established first. These stemmed from trauma which was an essential commonality of all the stories, inherent in the nature of the study. These themes of the beginning provided direction for the search for themes of the end, those of recovery as it is understood by persons with TBI. Meaning was refined by considering the complementary and oppositional relation of the themes of the end to those of the beginning. For instance, the theme of disorientation which emerged clearly in the beginning was then compared with end of story accounts of self-awareness and self-predictability which suggested a theme of reorientation. The experience of having a diminished role with other people was considered in light of experiences described at the end of the story. In those descriptions the importance of satisfying relationships was echoed by each person and became a theme of the end of the story.

The middle was then examined in view of connections which shed light on the transition from the beginning of the story to the end. It soon became apparent that the middle of the story was a working stage which divided naturally into two parts. Each person described demoralizing events which tore down his or her world. Without exception these experiences were negative. However, the same individuals also spoke of events which left them feeling hopeful and re-energized, experiences which were typically

positive in nature. There was a cycle of deconstruction and reconstruction with both forces being credited with important contributions to the achievement of recovery. For instance, GS was devastated to discover that he had been saddling the horses incorrectly but once he accepted this to be true, he made a decision which he considered necessary to protect himself and the animals he loved. The near fight with his best friend over rotting pizza sent SR into an emotional tailspin but he credits the event with forcing him to confront some of the changes he had undergone and challenging him to find ways to act more appropriately. When RS lost his apprenticeship he was angry and hurt but later on he made sense of it in two ways. First, he was able to understand the challenges he would have faced to complete his training. Second, after enduring other similar experiences he began to question his own responsibility for the outcome. He was able to acknowledge his contribution to his difficulties and consider ways he could react differently in future opportunities. In other words, each person was devastated by deconstructive incidents but those events became instructive, a springboard to reconstructive attitudes or activities.

Events which fell into the category of re-construction may be less surprising in their contribution to movement towards recovery and included SP selling her wheelchair so she would have to walk, GS studying despite headaches and fatigue to pass the college entrance exam and SR seeking and finding a job on his own. This presence of new possibilities emerged early on for JG when he complained about being a prisoner at the rehab hospital and was told by his family that he was free to leave anytime. His commitment to rehab changed when he evaluated what he was free, not forced, to do.

The emergence of themes in the middle, connecting the beginning with the end of the story also helped elucidate the differences between various levels of personal experience. The stream that began with disorientation and ended with reorientation illustrated profound, internal experiences. The stream which began with a conflicting sense of reality suggested a greater degree of acting in, as well as reacting to, one's external world. A third stream connected to the individual's interpersonal world and the fourth stream depicted the person's intrapersonal relationship, his or her sense of role and identity. These streams were not apparent at the beginning of the analysis but emerged through the comparative process.

Movement through the four parts of the pattern (trauma, deconstruction, reconstruction and recovery) is linear only to the extent that the story always begins with a trauma. There is an ebb and flow throughout the story. Progress is cyclical in nature. For example, JG's confrontation with his family over his prisoner status at the rehab hospital opened up new possibilities for him. This was a constructive event for him because it facilitated his active commitment to his treatment. This incident occurred relatively early in his recovery process and many events which followed were part of the theme of deconstruction. Even at the end of the story there is a fragility that imparts risk of regression to earlier states. SR stated that he felt content and confident in his life by the end of the story. He also noted that if he were to lose his job, this would throw into question his assumptions and expectations. He anticipated that such an event would set him back to problems encountered earlier in the process of recovery. In other words, the themes and streams are interwoven and dynamic. The parts interact with one another to

create the whole and the whole exerts influence upon the parts. Table 2 illustrates the recovery process incorporating the themes and streams described above.

Table 2

Themes of recovery from TBI

	TRAUMA	DECONSTRUCTION OF OLD STORY	CONSTRUCTION OF A NEW STORY	RECOVERY
INTERNAL	disorientation	helplessness	reasserting personal agency	reorientation
EXTERNAL	conflicting sense of reality	frustration	striving to actualize possibilities	synchronized sense of reality
INTER- PERSONAL	diminished role with others	invalidation	validation of adequacy	satisfying relationships
INTRA- PERSONAL	dissatisfaction with self	loss of meaningful role	identifying possibility of new role	satisfaction with self

TRAUMA

Trauma marks the beginning of the story. The individual is carrying on his or her life as usual when a sudden, unexpected, violent event shatters that familiar existence. Upon regaining consciousness, the person is disoriented. A critical incident has taken place and he or she has no memory of it and no understanding of its true impact. One knows nothing of the brain injury except the subjective experience of having trouble organizing thoughts. Images and awareness fade in and out. Acknowledgement of the presence of family and friends is episodic (SP,IG,SR,JG,GS). One may strike out at others, at the medical equipment that invades one's body, or be verbally abusive (SR,IG,JG). Behaviour is out of character but he or she is oblivious to this fact. The world has turned upside down and nothing makes sense.

As the disorientation subsides one encounters a new and disturbing experience, that of a conflicting sense of reality. This might best be described as a "what the hell is going on?" experience. Physical limitations, such as movements one cannot perform or only with considerable pain, are understood. These injuries are obvious and come with an expectation of healing and recovery of functioning (SP,JG,IG,RS,GS,SR). However, as the person makes physical progress, he or she is confronted by other people's assessment of who they are and what they are capable of. At home or in a rehabilitation facility, the person's expectations are in direct conflict with those of the people around them. For instance, a doctor asks SR to complete simple, repetitive tasks. This is mundane and insulting for an individual who was functioning well and maintains that image of himself. Unexpected difficulty with such a task has no logical explanation based on what the person knows about him or herself. It seems that in the eyes of other people, the person has transformed from a capable and independent adult into a checklist of deficits. Limitations are highlighted by others. Compliance with rehabilitation is undertaken because it is valued by family members or because one perceives having no choice. The individual consoles him or herself with the belief that the treatment will aid the recovery of physical ability such as mobility or speech (SP,JG,IG,RS).

The contradictory assessments of reality are predominant when the individual attempts to return to pre-morbid activities such as work, hobbies, or social events. He or she encounters strong opposition or is actually prevented from acting on those ambitions. Desire to return to work may be met with delays or rejection (RS,JG,GS). Driver's license and insurance is cancelled (SP,RS,JG,GS). A student is believed to be unable to

perform well enough to attend classes (SR). The person who lived independently has that privilege revoked (IG,SP). All of these restrictions fly in the face of what the person with TBI knows about him or herself, that he or she is a capable human being with a clear picture of what has been accomplished in the past and what the goals are for the future. Suddenly, he or she is being inexplicably treated like a child. The barriers thrown up around the individual make little sense and lead to frustration and anger in some, resigned and passive compliance in others. Interpersonal conflicts emerge from the incompatible views of reality. The individual's distress is compounded by relationships that become unexpectedly strained and stressful (IG,SC,SP,SR,GS).

The individual finds his or her place with others has changed in a negative way. In a diminished role with others family members and friends assume new responsibilities or may disconnect from the injured person. Some become reluctant guardians or treat the person as an invalid (SP,JG,GS,IG). Decisions are made for him or her. A person receiving positive support from loved ones is simply unable to fulfil the duties of previously held roles, such as that of a spouse, parent to one's children, caretaker of an elderly parent, or role model to a younger sibling (JG,GS,SR,IG,SC). Attempted return to work shows that encounters with employers and co-workers also change. One finds oneself in conflict with management over inability to perform necessary functions, being watched by peers and supervisors, and feeling puzzled, hurt, and intimidated as a result (RS,SC,GS).

Connected to all of these events, the person experiences a dissatisfaction with self. It is an internal, subjective sense ranging from malaise to outright self-condemnation.

The person is unhappy with him or herself and wishes to change this state of being.

Some respond to this by attempting to reassert the old self (SR,GS), while others place their trust in the prescriptions of others (JG,RS,SP,IG).

The attempt to reassert the old self is a forceful insistence on return to previous activities. These efforts are met with differing levels of success but typically encounter frustrating barriers. The person's determination leads him or her to unwittingly set unattainable goals (SR,GS). The attempt is either partially or completely unsuccessful. The fight against a faceless enemy is constant, exhausting, and obsessive. If the battle is prevented from evolving by a third party, the person feels betrayed, misunderstood, victimized, and angry (GS).

DECONSTRUCTION OF THE OLD STORY

The personal experiences subsequent to the injury create a disequilibrium in the lives of people with TBI. The beginning represents a time of learning that something is terribly wrong without knowing what that is. He or she attempts to regain some control in life while struggling toward some kind of understanding. The response to disorientation is to seek equilibrium, to make sense of the confusion. During this time the person seeks alleviation of the distress. However, the true situation combined with the person's impaired ability to assess it produces negative outcomes. Life unravels. Helplessness alternates with frustration. The roles that previously existed are lost and other people do not or cannot understand. They conspire to block the paths back to one's familiar and cherished lifestyle. It is a time of personal devastation.

An evolution occurs as the individual moves from receptor, in the first part, to

actor, in the second. Events and circumstances are significant individually and in combination. These pivotal moments contribute to the deconstruction of the old story. Critical incidents serve to unravel the threads which held together the original fabric of the person's life. These events individually (such as losing an apprenticeship) or repeated over time (such as receiving poor academic grades for several semesters) are emotionally negative experiences. They elicit responses such as shock, embarrassment, despair, abandonment, isolation, worthlessness, anger, bewilderment, sadness, disappointment, loss, confusion, frustration, helplessness, anxiety and an alarming realization of one's limits. The person is enmeshed in a working cycle as he or she strives to find a way out of the situation. In the darkest time one battles with depression, hopelessness, suicidal thinking, instability and worry regarding the future, and intense loss of self, of independence, and of the ability to achieve independence. One loses one's place in the social group or loses the social group altogether. The person is cast into a foreign and socially devalued group known as the "disabled". This can lead to a greater determination to re-establish one's old self by setting up structures which will promote such change.

All of the participants describe experiences or periods of time when they perceived no control in their lives. Six of them (SP,RS,JG,IG,GS,SC) related this experience of helplessness to their internment in rehabilitation facilities or at home. JG believed he had no choice as a "prisoner" at the rehab hospital. IG could not manage daily living responsibilities despite her desire to do so. RS, SP, and GS all were compelled to attend rehab without a sense of choice or commitment. SC could do little

more than sleep and have her young son care for her. When she did return to work, she couldn't help falling asleep even though she was responsible for the children in her charge.

The clashing constructs of reality encountered force the person to try to determine which reality is the correct one, to decide who is right and who is wrong. Attempts to rectify one's situation are met with frustration. Impaired self-awareness hampers one's ability to re-evaluate one's reality and make adaptive changes. The results are, at times, alarming. SR was shocked that he was fighting over stale pizza with his best friend. He was devastated by his uncharacteristic actions and the subsequent realization of change in himself. JG was shaken by his reaction to a speeding police car in his mirror, annoyed with his inability to deal successfully with a problem that a young child could have solved. GS knew he was doing his job well until confronted with the workstation manual he had apparently written. RS wanted to work but was easily annoyed and repeatedly quit on impulse. SC felt fully justified as she fought for her rights at the campsite only to be threatened with ejection and avoided by other campers.

Invalidation by others, intentionally or otherwise, serves to disintegrate self-esteem. It can be subtle or blatant but ultimately devalues the person in relation to others. For instance, SR considered the million dollar settlement conclusive proof that as far as other people were concerned, he would be unable to maintain employment in his lifetime. For GS the fact that close friends stopped calling or coming by confirmed his exclusion from the mainstream population. SP participated in a work trial at a daycare but discovered she was not considered safe to be left alone with any children. SC knew

something was wrong and reported her symptoms but was dismissed as a complaining and anxiety-ridden female.

The loss of meaningful roles is a huge decrement that occurs in the deconstruction of one's story. In telling the story of life before the injury, each person defined themselves by their roles. After TBI these are irrevocably changed. For example, RS was unable to complete his apprenticeship and move into the career he had anticipated since childhood. GS lost his riding and training licenses, his farm, his horses and his job. Gone was his place in the family's long and proud tradition. IG lost her career in which she was committed to helping others, and instead became the one being helped. SR was no longer a lawyer-to-be. JG would never again practice medicine. The loss of purpose, contribution and direction can leave one feeling helplessness, depressed and potentially suicidal (JG,SP,GS,IG,SC,SR,RS).

CONSTRUCTION OF A NEW STORY

Out of the devastation of the those events rises the potential for constructing a new story. The confrontation of harsh realities can be a motivating force. Combined with increasing self-awareness, the person is propelled to overcome the negative evaluations and find a path to renewed self-acceptance. Active interventions and revised behaviours evolve as one is able to acknowledge change and loss and relinquish unattainable goals. Challenges may be self-imposed (ie. making a decision to give up drugs), imposed by others (ie. doing volunteer work as part of treatment program) or simply coincidental (ie. meeting a neighbour with a disability). They may invoke surprise, excitement, pride, hope, relief, determination, a new sense of connection and enlightenment.

Despite the pain inflicted, these events are building blocks for a new direction in life. They lead to increased self-esteem and self-care, increased sense of agency, motivation and determination, reduced sense of isolation and enhanced sense of control and choice. They renew hope in accomplishing original goals but in a different way than previously envisioned (such as finding a rewarding career without a graduate degree), facilitate setting new goals (finding meaningful activities when return to work is not possible) and offer possibilities not present prior to the injury (such as entering post-secondary education). A new identity begins to emerge. Structures are erected or revised to increase the likelihood of success and steps are taken to deepen relationships or reconnect to mainstream populations.

In contrast to the early sense of helplessness, the construction of a new story is marked by re-asserting personal agency. The individual identifies some ways in which he or she can take control. It may be as simple as riding one's motorcycle to the social centre (RS), learning more about one's faith (GS), taking the initiative to call trusted a therapist for advice (SC), or seeking out a job independently (SR). SR refused a babysitter and insisted on his move to UVIC. JG learned to get himself to rehab appointments either by car or public transit. SP re-learned to wink. These acts lead to personal recognition of an acceptable level of recovery (RS), self-acceptance (GS,SP), progress toward a change of personal status (SC), or a realization of a desire to succeed outside the umbrella of rehabilitation (SR).

It is important to note that the cyclical nature of the pattern determines that reasserting personal agency will not always lead into themes of recovery. When such

reassertion is not successful, the person may find him or herself again struggling with feelings of helplessness. For instance, GS's return to work could be considered within the theme of disorientation or as an example of reasserting personal agency. If it is the latter, then the difficulties he encountered there contributed to further deconstruction of his story.

The frustration of being unable to perform familiar tasks is challenged by striving to actualize possibilities. Here the focus is on what one can do. New ways of being are embraced or tolerated. It lends itself to new ways of accomplishing original goals or it can point the way to new potential. Challenged by a trusted friend, SR was able to re-evaluate the routines he relied on and establish new, more flexible ones. After determining the importance of work in his life, he set out to get a job on his own. He accomplished this goal and was successful at it despite his ambivalence about the job itself. Later he sought and achieved a position he truly wanted. For JG the volunteer work arranged for him helped him understand that he could not return to his previous career but that he could contribute to patients' quality of life in a new and rewarding way. GS was encouraged to prepare for a college entrance exam. He had never considered post-secondary education. He worked hard to achieve this new goal.

Validation of adequacy is the re-building of one's sense of self in relation to others. Improved self-evaluation is echoed by others. Heightened self-protection combined with support from others helps the individual protect himself or herself from other negative evaluations. JG was heartened by the comments made by his nephew and endorsed by his son regarding his normality compared to others with TBI. SC received

positive feedback from her creative writing instructor, confirming her intuitions about her writing talents. SP was able to enjoy the care and support of her neighbours. This lessened the negative impact of her absent family who still treated her as an invalid. GS felt excluded and forgotten by his friends and peers but his relationship with God helped him find peace and acceptance within himself. IG's invitation to live with her daughter, as well as a chance at subsidized independent living, countered the threats to her sense of personal acceptability which stemmed from her son's warning of group home internment.

Within the construction of a new story, roles that were lost (the way the person used to define him or herself) are set aside to identify the possibility of a new role. Attention is turned toward who the person can become. For SR this exploration began after he confronted his inability to succeed further at university and accepted the need to dream a new dream. GS passed his entrance exam and assumed the brand new role of student. RS determined that he could attain a new and happier lifestyle by eliminating drugs and alcohol. JG embraced his increased interaction with his son and enthusiastically pursued his hobbies and volunteer work. He saw the potential for his development as an amateur photographer and committed himself to his charities, his church and his patients. For SC, the diagnosis of mild traumatic brain injury opened the doors to treatment, acknowledgement of the challenges connected with running the daycare and the likelihood of a career change. SP's encounter with a man with paraplegia lead to a renewed belief in her ability to attain mobility and independence. Her first relationship returned her to the notion of her own attractiveness and eligibility for marriage. For IG the future remained uncertain but she held the hope of publishing

her verses thus contributing in a new way and nurturing a potential within her.

RECOVERY

The end of the story is heralded by the merging and fading of boundaries between the challenges met in recovery or rehabilitation and those that are simply part of life's journey. Participants did not identify points of recovery but instead described processes which facilitated change. Some events were known to be transformational at the time, many others were better understood with hindsight. A gradual transition had occurred which left active rehabilitation and the injury as the primary identifier of self in the past.

In stark contrast to the nightmarish disorientation of the beginning, the person has achieved a re-orientation, not to life as it was, but to life as it is. The individual is in a predictable place where he or she can or must live. There is a sense of who one is, how one will act in given situations and what one might reasonably accomplish. Life is structured to avoid confronting deficits that cannot be overcome. The person does not anticipate any great surprises, the confusion has cleared and she or he has the tools to cope with the typical challenges of daily living she or he encounters. One may work and enjoy family and friends while another may be resigned to greater limits that encompass daily living. One has the ability to anticipate that which is to come and feels capable of managing it by taking one's own initiative and/or seeking assistance from an ally. Six of the seven participants (RS,SR,GS,SC,JG,SP) described a level of self-awareness, self-predictability and self-confidence which permitted them to feel oriented in their worlds.

The new story has been established and the clashing realities that shook the foundation of the individual's world give way to a more synchronized sense of reality.

Where conflict predominated in the early stages, the end is typified by a more harmonious view of oneself in the world. The individual is aware of persisting limitations and chooses activities and goals accordingly. Feedback from others reflects a unified view and friction is greatly reduced compared to the experiences in the beginning. Six of the participants had achieved this state.

Satisfying relationships refers to one's ability to enjoy voluntary, non-dependent ties with family, involvement in intimate relationships and comfort in friendships. It also refers to one's ability to accept authority from an employer and to co-operate with co-workers. The connections to people, as described by the participants, ranged from pleasurable to challenging to extremely limited. RS is close to his family and happy with his intimate relationship. He still hopes to improve his ability to collaborate productively in a work environment. SR is also involved romantically as well as maintaining close ties with family and friends. JG found a new way to be a contributing member in his family. He enjoys contact with people ranging from patients to friends to colleagues. SP is devoting her energy to her relationship with her future husband. She still struggles in her dealings with her family of origin. SC cherishes time with her son and has the support of her family and friends. GS has visits from his children but believes they are ashamed of him. His primary support, his father, is hospitalized and incapacitated. He spends most of his time alone.

Another theme which emerges at the end is that of satisfaction with self. The individual is content with him or herself. Self-deprecation that was present in the beginning has given way to a healthier self-regard. One person may feel a new kind of

self-confidence. For another, the reward comes from having re-evaluated one's life and made choices to embrace values which were minimized prior to the injury. The goals are the same as their pre-accident goals (such as work, play and family) but the specifics have changed. Four of the seven participants described themselves this way. SR loves his work, his girlfriend, activities with friends and his family. The big picture is in-line with his previous expectations. The details are different. RS feels good about his recovery and proud of his personal development. He met the woman he will marry and feels a growing confidence that he can manage his anger well enough to get and keep a job. SP's journey brought her to a lifestyle which makes her happier than she was before her injury. JG is busy and happy. His life includes people who enjoy his company and his laughter.

For all of the participants the journey was a long and arduous one. The path was not clear and the future was unknown. SR fought relentlessly for the goals he desired. The brain injury was never his cause, it seemed to be more so for people around him. He simply wanted to fulfil his right to a happy lifestyle which included rewarding work. RS needed a certain level of physical functioning and behaviour which did not render him visibly different from other people. Once he had accomplished this he was satisfied that he could seek out meaningful life goals. JG re-organized his life to the point where he no longer thought of himself as brain-injured. His life was full and he did not look back. SP planned her marriage and learned to walk without the aid of a wheelchair. GS adapted to greater restrictions in his life. His seizures and fatigue significantly impaired his productivity, outside activities and social interactions.

DIVERSITY

The purpose of the analysis was to define, if it existed, a common pattern of recovery of the study participants. Themes, as they emerged, came from different life experiences that had a shared meaning. The pattern that has been presented draws from those experiences and shared meanings in general. There are some specific situations in which an individual's account was dissimilar to the others.

Two of the participants, SC and IG, had stories which differed from the others. Both had been injured more recently (SC, four years ago and IG, three years ago) compared with the others who averaged eight and a half years of recovery. SC's brain injury remained undiagnosed for two years. While others were trying to move away from the label, SC was struggling to find one that fit and could point her in the direction of rehabilitation and recovery. While most participants perceived over-emphasis of the injury by others, SC was thrilled when her injury was finally recognized and her concerns validated. IG's story showed her to be in earlier cycles of her recovery. Events she described were of trauma and deconstruction of her old story. There were few that had yet emerged to help her construct a new one.

The progression from trauma to recovery seemed to occur as a series of mini-cycles. The experiences of trauma were quite consistent and most accounts suggested the person moved from there into the deconstruction. This cycle evolved to alternate between deconstruction and reconstruction. Some of these events could potentially trigger again the themes of trauma. This interaction continued until the construction theme became more stable and prominent. This state seemed to be a necessary

prerequisite to moving into recovery. For instance, JG struggled to establish himself in new activities. His life became more predictable and stable as these were consolidated. SR's account differed from this pattern in that he moved directly from trauma into reconstructing his old story. His determination to proceed to university in Victoria, pursue his ambitions for law school and generally live life as it had been, meant that he was not describing helplessness and loss of meaningful roles early in his story. However, when his attempts were thwarted over a period of time, he then described greater susceptibility to helplessness, frustration and fragile self-esteem. For instance, after being fired from his job he did not pursue school or employment for eighteen months. When he returned to university and realized he could not pursue graduate school he confronted the fact that he no longer knew what the future held. He then struggled with this deconstruction of his former story and subsequently was able to move toward reconstruction, this time of a new story.

CHAPTER XII

DISCUSSION

In this study the researcher interviewed seven voluntary participants individually on two occasions. The length of time since the injury ranged from three to eleven years. The intent was to seek out the insight and wisdom of the storyteller. The product of this study was two-fold. First, it generated seven accounts of recovery from traumatic brain injury from the perspective of the individuals who lived it. Second, it produced a pattern of recovery gleaned from the comparison of these rich and unique stories. This offered fuller understanding of the meaning of recovery and the significance of critical incidents within the process.

The common pattern which emerged showed that the precipitating physical insult is followed by intense emotional trauma as the person struggles to understand what has happened. The person tries to return to a previous lifestyle but fails in the attempt. Over a period of years the individual identifies abilities and possibilities that guide him or her toward positive change. Eventually, some level of stability and predictability facilitates movement away from brain injury as a personal identifier and away from recovery as a goal.

The progression from trauma, cycling through deconstruction and reconstruction, to recovery presented in four streams. These streams reflected personal experiences on different levels. The internal stream reflected the struggle that occurred within the person and included disorientation, helplessness, reasserting personal agency and reorientation. The external stream referred to actions and reactions in relation to the

world around and encompassed conflicting sense of reality, frustration, striving to actualize possibilities and synchronized sense of reality. The interpersonal stream pertained to relationships and cycled through a diminished role with others, invalidation, validation of adequacy and satisfying relationships. The intrapersonal stream referred to one's relationship with oneself and ranged from dissatisfaction with self, loss of meaningful role and identifying the possibility of a new role to satisfaction with self. The process is dynamic and the streams are interconnected.

LIMITATIONS OF THE STUDY

One of the limitations of the study involved the participants ability to remember and articulate all that has happened to them. Each one admitted having had problems with memory and self-awareness. This means that some events may have been recalled inaccurately while others may have been forgotten. However, for the purpose of this study, factual accuracy was not considered to be as important as lived experience. For instance, if an individual was fired from a job due to incompetence but the individual experienced that as a unfair and unjustified penalty, it is that latter account and the personal repercussions that were valued in this case. The opportunity to review their accounts in written form also afforded each participant the chance confirm or correct the description.

The volunteers for this study were not selected based on a medical or neuropsychological diagnosis. In other words, the study was not limited to individuals diagnosed with for example, severe brain injury. Diagnoses were set aside in favour of qualitative criteria such as ability to recall and articulate one's experiences, desire to tell

one's story and emotional distance sufficient to protect personal integrity. As a result, the participants as a group probably spanned the breadth of the diagnostic categories. Clearly, however, they represent only a part of the group known as survivors of TBI, many of whom are unable to meet the qualitative criteria described above. Since participants were not screened by severity or location of injury, the study cannot address possible differences of psychological impact attributable to such factors. Comparisons of a general nature are made, such as between GS who is more severely restricted in daily living compared to SR or JG who are very active.

The case study methodology relies on replication of common results to make a distinctive pattern of recovery from TBI more plausible. In this study seven participants exhibited common themes in their transitions. It should be noted, however, that this does not infer that such a pattern is common to all individuals recovering from TBI. Results refer to the seven participants in this study.

The researcher's efforts to uncover the meaning of the participant's story can fall prey to one's own perspectives and level of sensitivity. I have attempted to minimize my influence in the results through several approaches. First, narrative accounts were reviewed by the participant to confirm accuracy and completeness. Second, an external reviewer compared the interview transcripts with the narrative accounts to ensure they were not influenced by bias, distortion or omission. "The narrative accounts accurately reflect the interviews with the participants. Participants were able to clearly tell their own story without interference or bias by the researcher. The narrative accounts did not neglect anything of significance in the interviews nor did they seem to distort the content

or presentations of the speaker" (independent reviewer). Third, each theme which emerged during the data analysis was checked against the protocols to confirm its validity. Examples from the interviews were presented in each case to support the inclusion of the theme. Finally, a doctoral supervisor was consulted over the course of the study with regard to the materials and the procedure.

In this study, theoretical attention was directed toward present recovery models and to theory building. The results could be strengthened by expanding the review to comparisons with a broader base of models or theories such as those of personal agency, construct hierarchies, needs and development theories.

IMPLICATIONS FOR THEORY

Keith (1993) and Keith & Lipsey (1993) addressed the need for theory-building in the field of rehabilitation. They targeted the need for a framework to explain the nature of recovery and the way treatment produces change. To that end, the intent of this study was to better understand the nature of recovery from TBI, not as documented by specialists or as described by family members but as it occurs and is perceived by those experiencing it. Such knowledge is an important step toward understanding what the rehabilitation goals should be and how intervention strategies can produce the desired changes.

Current theories identify four general categories important to recovery; emotional and personal adjustment to disability (Dembo et al, 1956; Vargo, 1989; Wright, 1983), societal attitudes and environmental conditions (Dembo, 1970; Vash, 1981; Wright, 1983), inclusion in significant relationships (Martin & Gandy 1990; Vash, 1961) and

participation in community, work and recreation (Henderson & Bryan, 1984). These factors align with the streams described by participants (internal, external, interpersonal and intrapersonal) over the course of recovery.

Wright's (1983) value changes (enlargement of scope of values, subordination of physique relative to other values, containment of the effects of spread and transforming comparative-status values into asset values) proposed for rehabilitation in general find some support within the stories of recovery from brain injury. Those in the study who could be considered successful in their recovery spoke primarily of what they could do, focusing on valuable aspects of life which were available to them. SP, while wheelchair-bound, went from despair to determination. She was able to challenge and revise the negative and limiting view of herself which she connected to her restriction to a wheelchair. Although most of the participants (five out of seven) demonstrated some physical restrictions, those who considered themselves finished with the rehab process did not dwell on, or in some cases even mention, those physical sequelae. It should be noted that physical disabilities stemming from TBI may improve over time and thus the issue of physique may differ qualitatively from an individual who has suffered, for instance, a permanent spinal cord injury. Equally important is the fact that TBI is often a hidden disability. Many people with TBI show no visible signs of injury. For these people, physique is a non-issue.

The restriction of spread (the containment of the effects of disability) may underlie some of the differences between those who were content with their lives and those who were not. All described times in which their injury imposed a global effect upon their

lives but most were engaged in non-disability related areas (such as relationships, family, friends, hobbies, work and travel) by the end of their accounts. Finally, the ability to set one's own standard, rather than a comparative one, was also present by the end of many stories. SP was thrilled when she finally was able to jump. RS sought work for his own fulfilment, not because of what his friends thought. JG loved his activities and expressed no concern for what his former colleagues might be accomplishing. SR's pride in his work with street kids betrayed no trace of comparison to what he might have done as a lawyer or compared to what his friends were doing. It is interesting to note that Wright's attention to the role of values in psychological adjustment to disability is rarely mentioned in the brain injury literature. Perhaps this is because she addresses the intrinsic meaning of experiences to the individual in a way which has been overlooked with this population. Another explanation might be that while consistent with Wright's concepts in general, the stories of individuals with TBI require a specificity that extends beyond broadly-defined rehabilitation.

Societal attitudes and environmental conditions as a category important to recovery help underline one of the key points of this study, that the person doing the experiencing must be differentiated from the person(s) doing the observing and evaluating. If change is to occur societally, environmentally and within the realms of treatment interventions, the perspective of the person with the injury is required. The accounts provided in this study lend support to Wright's (1983) description of client as co-manager and McDonald & Crozier's (1992) call for a consumer-driven model.

Inclusion in significant relationships is clearly indicated to be important according

to the participants in the study. Vash (1981) stated that the family is not a component of the rehabilitation process, the family is the client. All participants spoke of the role of family in their recovery process. Clearly family members should be invited to be actively involved in the rehabilitation program. However, the tone of the participants' accounts indicated that at least at times they were adrift on a solo journey. No matter how much, or how little, support the person experienced, each one spoke powerfully about very personal events and reactions, some of which they had not shared with anyone else. That said, it appears that the importance of significant relationships cannot be overemphasized. Martin & Gandy (1990) claimed that family members can be collaborators in instilling value change. This phenomenon was perhaps best illustrated by JG. His wife and son's challenge allowed him to re-evaluate his approach to his rehabilitation. Their ability to revise family roles to accommodate change while still demanding important daily contributions from him, likely formed the base of the meaningful lifestyle which he created. From the words of the participants, the support of people who matter is transformational. Equally powerful is the pain induced by the absence of such support.

The importance of participation in community, work and recreation is also well-documented in the accounts of this study. Based on the recognition of isolation as a frequent and devastating result of brain injury, this group seemed quite exceptional. Only one of the participants (GS) seemed to be excessively disconnected from close social ties. IG also spoke little of people other than rehab workers and family but she was also earlier in her recovery. The streams lend support to the approach of brain injury

researchers (Bond & Brooks, 1976; Prigatano, 1987; Wood, 1989) who posit that psychosocial problems must be assessed with regard to pre-morbid personality factors, family dynamics and potential for employment. Regarding the latter issue, Prigatano (1991) addressed the need to expand the boundaries of the culturally-based value on employment to include other meaningful activities. Study participants presented end-of-story themes which were intrinsic and deeply personal and for which employment was not necessarily their final goal. The accounts supported the expansion of the definition of work away from a strictly employment-based model, to one which encompasses any regular, meaningful activity. SR didn't need the money but he did need to be challenged and to contribute to society to maintain his self-esteem. JG was busy and felt useful and fulfilled despite not having 'a job'. GS missed his job and his income but he grieved the loss of his life with horses. SP and RS placed other values, such as relationships, above work.

Phase and stage theories have been utilized despite rising criticism and lack of empirical evidence (Henderson & Bryan, 1984; Livneh & Antonak, 1990). The idea of pre-set stages was challenged by Wortman & Silver (1987, 1989, 1990) who showed that study participants did not meet all stage requirements, that achievement of resolution did not always occur, that it took longer than expected when it did and that individuals reported suffering less than the models predicted. The results of this study also fail to support the stage theory approach to recovery. The data from this study suggest a dynamic process in which the individual's experiences and reactions serve to deconstruct a previously held story and to reconstruct a new one.

Adjustment and acceptance are often listed as key goals in rehabilitation (Henderson & Bryan, 1984; Kerr, 1977; Prigatano, 1986; Shontz, 1977; Vash, 1978). Typically, these terms seem to be used to describe an individual's admission of deficits followed by use of compensatory strategies to minimize their impact. According to this study, individuals do not just admit their deficits, adapt to a new role or accept their status as disabled persons. Recovery encompassed a multi-dimensional sense of reorientation, synchronized sense of reality, satisfying relationships and self satisfaction.

Dembo et al (1956) defined their notion of acceptance of loss as a process of change in values, not a reconciliation to an unfortunate situation. The accounts in this study align more closely with this latter view. Some participants mentioned acceptance but it did not emerge as a theme of their experiences. Only one person identified acceptance as a way of coping with the severe restrictions he continued to deal with at the end of his story. For others, it seemed to be a transient factor within the middle of their stories, not a final goal as posited in the literature. This offers a departure from Dembo's hypothesis in that change of values appears to be a cyclical process and not just an end result. The end of the participants' stories suggested that value changes were already resolved and the individual was carrying on his or her life without specific attention to them. For instance, JG said acceptance was essential to moving on and building a new story. By the end of his story that acceptance had a distant quality, not a strong current presence. RS came to accept his impulsive anger, not so that he could tolerate it, but so that he could learn to change it. SR did not accept himself as anything less than he was before the injury but he did come to accept that he could not become a

lawyer which liberated him to find a new career. To summarize, the notion of acceptance as described by these people was not a resignation of oneself as a disabled person. Rather, they accepted specific limitations so that those limitations could be accommodated or overcome en route to their destination. This process facilitated movement toward recovery but was not a marker of the achievement of recovery.

IMPLICATIONS FOR PRACTICE

The rehabilitative treatment of traumatic brain injury evolved practically because the clinical need preceded the establishment of a sound theoretical base. In the past decade we have witnessed theory gradually catching up to practice. Empirical data has provided much needed information about the multi-faceted challenges faced in treating a person with brain injury. However, the practitioner as expert model had taken root and it has been implemented to justify prescribing what is supposedly known to be best for the injured person. The stories in this study open a window into the complexity of what the person with TBI goes through. While many clinicians are familiar with their stories, the literature has not fully addressed or supported it. Such understanding is crucial to determining the ways in which treatment programs can collaborate with, rather than dictate to, the recovering individual. It stresses the need to align with each person as an individual, not as a set of behaviours. For instance, anticipating that an individual with TBI will become disconnected from pre-injury friends or working on social skills to develop new friendships does not replace the need and the value of hearing, understanding and communicating one's understanding of the person who grieves the loss of a friend.

The individuals in this study did not go through stages of recovery. They provided insight into a cyclical and dynamic process with many layers and dimensions. Acceptance was not the achievement of a final stage but was in fact, a repetitive theme throughout the middle of the story. The evolution of recognizing, acknowledging, understanding and adapting contributed to both deconstructive and reconstructive events. It was identified as a necessary process to feel more firmly established in reconstruction of one's life. In hindsight and through telling the story, the importance of deconstructive and reconstructive events was understood by the person. They represented the blocks on which their new lives were built.

The relevance of this information to practice is clear. Assuming that all, or even most, individuals go through pre-conceived stages toward the goal of acceptance may not be accurate. A treatment program based on this assumption may not meet the needs of its clients. In fact, such a program risks further reducing the individual's sense of self, sense of agency and his or her need to feel understood, all of which have already been damaged by the injury itself. This study's results support those presented by Condeluci et al (1992) in which survivors identified self-esteem, self-awareness and improved social skills as being as important to them as behavioural changes presented in treatment programs. This study extends previous work by gaining an understanding of the meaning attached to experiences within the recovery process. Only the individual with TBI can provide that perspective and by doing so, offer insight into his or her needs. Thus, the practitioner armed with knowledge and expertise must meet the individual halfway to determine their outcome values related to quality of life issues.

The dynamic process of recovery described in this study has implications for the funding of treatment programs. Fee-payers typically seek behavioural changes which offer optimum independence and preferably, return to work. Within a stage model such defining criteria may be attainable. The results of this study however, suggest that true recovery does not proceed linearly or necessarily by acquisition of specific skills or behaviours. This study posits that recovery evolves from the individual's struggle within him or herself and with others, through a tumultuous process, to attain a quality of life which is meaningful to that individual. It is not measured by the ability to take a bus or to get a job. It is measured by the person's groundedness and sense of being in sync with the world. It is measured by the person's ability to be meaningful connected to other people and by his or her own intrinsic criteria for self-satisfaction. The challenge then, for the financial supporters of treatment of TBI is the acknowledgement of the length of time the process can take (for this study's participants ten years would be a reasonable estimate) and that the individual's assessment, not his or her measurable behaviours, be the standard for recovery.

This is not the bad news it may seem in light of current economic cutbacks. Participants who felt misunderstood or neglected during the course of their rehabilitation treatment identified this as a crucial gap in their progress. Those who did feel supported noted the importance of such an experience. Clearly, the motivation of the individual has implications for possibilities of restoration. The question is how to facilitate and expedite, rather than re-direct or derail, recovery.

The role of the counsellor in the rehabilitative process is an important one. As

well as offering an unconditionally supportive relationship throughout the painful and joyful journey, the accounts in this study can serve as a guide to the counsellor and the individual with TBI. The model presented here offers a new way of conceptualizing each person's experiences in such a way that both parties might better understand the meaning of events as they occur and anticipate and normalize the recovery process so that it may be less traumatic. For example, SR's incident with the pizza could have been dealt with first, by working through the shock and pain of his realization of change, then by exploring the potential benefits that the experience might have uncovered, and finally by determining how to execute and evaluate the desired steps.

All of the participants in the present study had some involvement in treatment programs. Their most common complaint was in feeling coerced into fitting treatment guidelines. In this approach, the practitioner joins with the person to collaboratively work through a necessary process. The person living the experience is given a voice in how to do that. SR spoke strongly against a medical, legal and rehabilitation system which promoted negativity. "The more and more positive things that were introduced to me, the better off I was. And I think that its almost, sadly that almost a silly, such a simple point to make. I don't think you have to be brain injured to realize that that's helpful...you just take a normal everyday Joe who is a great carpenter and tell him he's smart like a truck its not very helpful. Tell him he's a great carpenter, tell him you'd love to see him build a cabinet for you. That's really good for him." Clearly his emphasis was on identifying what he could do and he fought against the deficit-based model embraced by others. Using this model, SR's message could be heard and acted

upon. A therapeutic goal would become the identification of abilities and possibilities. Life situations could be reviewed in hindsight, or rehearsed in anticipation, with this philosophy accommodating the process. Less of his energy would have to be expended fighting negativity imposed by others, leaving more to cope with the practical day-to-day challenges and to work toward construction of his new story.

Ben-Yishay & Prigatano (1990) report success using cognitive therapy to advance their patients through a hierarchy of distinct stages. Their patients graduated after they had shown improved self-awareness, developed compensatory strategies, accepted their deficits, let go of their pre-injury goals and expectations, planned a new and realistic future and re-entered the community. If we consider the perspectives presented in this study, criticism lies not with the treatment itself but with the manner in which it is prescribed. The study participants wanted all of the achievements described above but as they applied to their own unique circumstances. Some noted the importance of making their own mistakes. The sequential nature of treatment program differs from the results of this study in which the process, diagrammatically, might resemble a helix rather than a set of steps.

IMPLICATIONS FOR FUTURE RESEARCH

The first step with regard to future research is to discover whether the accounts described in this study share similarities to a broader population of individuals with TBI. This could be accomplished by preparing a survey which would be completed by larger numbers of participants. This would permit a wider sample of individuals and selection criteria could also be adjusted to provide more detailed information. For instance,

medical diagnosis of mild, moderate and severe brain injury could be used and age or gender differences could be studied. A survey could be designed to permit participant evaluation of treatment programs, both at the time of completion and several years later. When employing a survey, care should be taken to make sure that it is completed by the person with TBI rather than a family member or friend. The types of questions and means of responding (such as multiple choice) must be carefully considered with regard to the type of cognitive difficulties that might be encountered. Finally, it should include either a section for comments or be followed by an interview to ascertain how it was completed and to get the person's reactions to the task, to ensure meaningful results.

If replication studies support the findings of this research project, it would be worthwhile exploring critical incidents which make up the deconstructive and reconstructive aspects of the middle of the story. For instance, what determines how an event will affect that individual and how it will be utilized? Are there typical events which occur? If so, does the timing of their presentation have any significant impact? Further information might provide valuable information about the differences between individuals whose recovery is less successful and individuals whose recovery is more successful.

The idea of recovery has been defined by researchers and theorists and not by individuals with TBI. The term itself was noticeably absent in the language of the participants. When asked about recovery, several of them requested explanations or definitions. It seemed to be a difficult concept to understand or explain. Two brief excerpts from interviews illustrate the point:

PL: And it sounds like that kind of sums up where you are now in terms of recovery.

I don't know, does this still feel like recovery for you or is there...

SR: Is there an end? Oh, that's an interesting question. I don't know. I think that different points in your life feel like recovery, different points of my life have felt like I'm in need of recovery. For me now I feel less and less like I'm in need of recovery. I always had a few goals in life, you know sort of like to fit that picture of my lifeline. One of them was my career, I was going to be a lawyer. I guess if you look back to when you're in high school you kind of have this picture of yourself, you're so old say you're 25 and you're already a lawyer and you're making \$500,000 a year, you're married with this beautiful family and everything is just marvellous. Of course that doesn't pan out and you learn to accept it, that's ok and I think that for me recovery was learning to deal with how that didn't pan out. And at different points in time, different things were difficult. Right now I'm in a wonderful relationship, I have a career I love. You know right now I don't feel that there's too many areas of my life that I need to do a lot of work on, to be really truthful.

PL: So even though its not the picture that you had in high school looking forward, the picture as it is now is one that you feel good about.

SR: Yeah, I'm very happy with my life. I don't know how different my picture today is from what it was in high school. I mean I'm not a lawyer and I don't have 2.2 kids and a little minivan in the driveway but its not altogether different than what I sort of dreamed of. I'm happy in my career and I'm happy in my relationship,

how much more could I have expected.

PL: It sounds like you expected yourself to be happy with yourself and challenged in your career and enjoying what you were doing and being in important relationships. And it sounds like that's where you are.

SR: Yeah, it certainly went a different road than I expected but I think that's pretty fair to say of everyone. How many of us would have anticipated this path from high school, I don't know very many. So yeah, at times I certainly feel like I'm still in recovery and others times when things are going pretty darn blissfully, then no I'm not in recovery, I think things are pretty darn blissful for me right now I guess. So I don't feel too, too much like I'm in recovery.

PL: When you look back is there a point at which recovery ended?

SR: No.

PL: It almost sounds like it's there in the background but there's times when you turn more to it and you think ah hah I need to work on this or that and other times like now where it's not...

SR: I would say that if there is a definite point where recovery ended...I would say the most important point for me was when I finished my probation at work. You know I felt like I could be here, my career is done. That was the most important struggle.

With another participant:

PL: I've got one last question I might ask of you and it's a hard one to answer, I don't know if you can...I'm wondering, does one ever recover from brain injury?

JG: Does one ever recover?

PL: Have you recovered from brain injury?

JG: Like ah, what...is it anatomically.

PL: No just in terms of life, in terms of living your life. The term recovery means return to original level of functioning but I think we also think of it as just getting better. So that's what makes it a tough question.

JG: It is yeah. Anatomically of course, no!

PL: Day to day living?

JG: Day to day living, yes.

We need a revision of the notion of recovery to include the perspective of the person living it. This study proposes a place to begin.

SUMMARY

At this point I would like to offer a personal perspective and reaction to the findings of this study. My clinical work with individuals who sustained traumatic brain injury, and their families, began ten years ago. My training was in counselling psychology. My knowledge of neuropsychology was limited. The literature was primarily diagnostic and offered little that seemed to coincide with my early clinical experiences. Favouring a client-centred model which values the perspective of individual, I learned about TBI from my clients. To understand their plight, I listened hard and applied my skills. It was soon obvious to me that my listening represented an unusual encounter for them. They had been assessed by medical experts and directed by lawyers and insurance adjusters but had not felt heard when they told their stories. Many

were reluctant, in our early sessions, to repeat the now memorized story yet again. I was frequently directed by these clients, to reports written by one expert or another. Months or years of interventions from experts seemed to contribute to the person's helplessness and self-doubt, and promoted assigned recovery instead of a personal journey to an unknown destination. With encouragement they acquiesced and told their stories (often using terminology which was suspiciously clinical in nature). Their reaction to my reflections and interventions was enlightening for both of us. I treaded lightly for some of the early writings suggested that people with TBI could be overwhelmed by counselling, unable to moderate their emotions or make sense of their distress and thus it would become heightened and entrenched. Sure enough, as they explored their changed lives, their confusion and their fears, many of them became depressed. Consultation and supervision with an experienced neuropsychologist assured me that we should continue. As with my non-TBI clients, they began to present me with new insights and new hope. We struggled together to find ways to use these learnings practically and appropriately. Just when I thought a client had 'adjusted', a new crisis would shatter that optimism. Each time though, I had an impression of strengthening on the part of that individual, an increased resiliency and over time, increased self-understanding.

I found myself reacting to some of the assumptions which seemed prevalent at that time. For instance, individuals with TBI were often said to be in denial of their injury and its behavioural and cognitive sequelae. It was confirmed over time for me that they lacked awareness of aspects of their world. This is a vastly different phenomenon than psychological denial. There also seemed to be a subtle sense of each person being 'less

than' they were before. This made the expert role an easy one to fall into. It pervaded professional behaviour and led for example, to decision-making conducted without the presence of the individual who was affected by it.

Having pondered the outcome of this study, I submit the following thoughts on ethical and effective treatment. The basis of most counselling is the establishment of the therapeutic relationship. A few factors work against this at the beginning but the crucial one is the conflicting sense of reality. The experience of 'being fine' but confronting contradictory messages from other people left some participants feeling suspicious and distrustful. Most described treatment that was assigned but not embraced. Their impression was that all would be fine once they returned to previous activities. The challenge is to create a safe environment for the person who has been labelled 'patient' but doesn't feel like one to express his or her true feelings and to help generate some personal motivation to continue.

The therapist attitudes promoted by Carl Rogers (1961) of genuineness, unconditional positive regard and accurate empathic understanding are simple qualities on which the relationship can be built. Rogers' philosophy seems well-suited to working with the individuals and their stories. It assumes the individual has the capacity to seek and find his or her own solutions and is motivated toward self-actualization, to becoming one's true self. The true self refers to the integrated self, not the self whose experiences have been distorted or denied as a result of significant other or environmental influences (Rogers, 1951). This approach leads to the very heart of the stories of the participants, namely their desire and their struggle to find a self they feel satisfied with. It is apparent

that having suffered a brain injury did not block, and may even accentuate, this human capacity.

The reason for promoting this approach is in reaction to the traditional expert model which seeks to assert rather than to ascertain. The stories of the participants clearly depicts many experiences of not being heard or understood. If one is to undertake a collaborative tack in the rehabilitation, it makes sense to start with a client-centred base. Treatment however, must not be confined to self-reflective talk therapy. Interventions need to be active while maintaining an atmosphere of unconditional support. Plans for active change must be designed and executed, with the therapist facilitating opportunities or engaging other rehabilitation specialists (such as life skills workers or occupational therapists) whenever appropriate. The person with TBI is trying to maintain a positive sense of him or herself but encountering frustrating, invalidating experiences which contribute to feelings of helplessness and loss. In the therapeutic milieu the person can safely experience or explore them without fear of judgement or imposed correction. The counsellor's role is to facilitate further interpretation of experiences and to offer guidance when appropriate. Questions of recovery, grief, basic needs, identity, relationships, sexuality, vocation, recreation and so on, must be addressed.

While I am not surprised by the richness of the stories presented by the participants in this study, the pattern which emerged from their stories was novel. Further studies are needed to validate and extend the results of this study. Educating the person with regard to the dynamic process could be productive. This could serve to reduce some of the associated trauma and facilitate efforts to determine the purpose and

potential benefit of trying experiences. As the person cycles through deconstructive and reconstructive events, those events can be assessed and understood together.

Collaboratively, situations can be tested and revised in accordance with the individual's need at that time. For instance, if an individual needs to attempt a return to work despite indications that he or she will not succeed, and if it can be safely arranged, the trial can be embarked on together so that the process, as much as the end result, offers further guidance and direction.

The therapeutic goal within this model is not to achieve acceptance of oneself as a brain-injured individual, it is to work through the trauma and the deconstructive and reconstructive processes to achieve a new story. The destination is a safe, predictable and personally satisfying place which has subtly merged with life in general.

An important factor in deciding to pursue this research was adherence to a scientist/practitioner model. My aim was to contribute both theoretically and clinically and to utilize an approach which honoured and collaborated with the people who donated their time and their stories. It seemed reasonable to give something back while contributing to professional knowledge. Collectively they presented a new way of understanding the experience of recovery from brain injury. This knowledge needs to be incorporated into our treatment programs. Each person also had ideas and reactions which provided insights into individual quality of life issues. This specificity must not be sacrificed to a broader conception of traumatic brain injury.

At the end of the second interview each person was asked whether there was anything he or she wanted to add. Here are a few of their concluding thoughts:

PL: If they had listened to you then and said we're going to do whatever S. asks us, that probably would have been a mistake.

SP: A very bad mistake. S. would have ended up back in the same rut. The drinking.

PL: What you're saying is that you may not always know, especially in the early stages what's best for you.

SP: I don't think you do know it all.

PL: Its a fine balance between talking to you and finding out what's important to you but also having people with some other knowledge to help you make decisions.

SP: Like listen to what I have to say, take into consideration what I want but that consideration will be...

PL: You might not get everything you want (S: That's right) but that might be for the best.

SP: That's right. At least you've listened to what I've said.

PL: And that in itself sounds like it would be worth something to feel like they were listening.

SP: Yeah, for sure.

SC: I don't know that I've emphasized it enough but certainly the psychologist, seeing her every week to deal with the anger and just the intense feelings that I was having because I couldn't understand why. I didn't consider myself ever to be a very emotional kind of person, I considered myself to be more of a Mr. Spock from StarTrek, the very rational, logical and this crying stuff all over the place really doesn't seem to be me and I

think having her assist me with understanding emotions a bit better and dealing with emotions has been tremendously...and decreasing those emotions of anger...I don't know, I probably would have committed suicide by now. You can't live with people telling you all the time, well you said you were going to do this and then you think to yourself, no I didn't say that and you don't have it written down so you don't know that you did say that and then you are getting it from everybody. It would be different if it was just one person and you could say piss off and leave that person out of your life and then your life would be fine but when you are getting it from friends and relatives and your own kid and everybody is telling you the same stuff about your memory and that you said you were going to do this and you haven't and you have no way to remember what you did say or what you didn't say.

PL: Its like you can't defend yourself.

SC: You can't defend yourself and you can't feel that you really know what's going on and if you can't feel like you know what's going on, like where are you, you are not operating in this world, if you don't know what's happening. And so I think that without both of them, the psychologist and the OT, life...I mean I thought I was dying when I saw the psychologist, I really thought, god this stress and anxiety stuff is killing me, I'm dying. I think of death and dying and I'm dying. Part of me doesn't exist any more. I'm dead.

PL: Is there anything you want to add or anything we've overlooked?

RS: I just wish this sort of thing was done ten years ago so I could have got a guidance

counsellor out of it I guess. I don't know if that'll come around. I hope it does for people because there's lots of head injuries out there, lots of people don't have any goals, expectations to live life. I could have done a lot more with my life than I have if I had some sort of positive guidance.

In summary, the findings which seem particularly pertinent to this researcher are as follows. First, amongst the chaos of traumatic brain injury there may be order embedded in the patterns the participants described. This order evolves from the meaning they attach to their recovery. It is not a structure imposed by current theoretical models or treatment programs. Second, individuals with TBI describe an experience which is not conceptualized in stages. Rather it is cyclical and dynamic and encompasses themes and streams which are interwoven into the fabric of recovery. Third, the rehabilitation treatment received by the participants was not criticized for what it offered so much as for what it did not. Rehabilitation was seen to be imposed and deficit-focused. There was a general agreement that, to a greater or lesser degree, the experience of the individual was minimized, ignored or misunderstood. Their determination to overcome adversity often included challenging or bypassing the very resource which was supposed to support and encourage them.

The meaning of an experience such as recovery from traumatic brain injury requires the perspective of the individual who lives it. The coherent story which emerges is, in some ways, an obvious one but it has been overlooked in the research. It has not originated from the assessment of professionals or family members. The story of the

person with TBI has surfaced with its own slant on what is endured. This information is crucial to the experts who design and assess treatment programs, to the family and friends who need to understand so they can support and assist appropriately, and to the individual with TBI so that he or she may find comfort and assistance in the difficult journey to recovery.

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APPENDIX A

Recruitment Notice

Researcher: I am a doctoral student in the Department of Counselling Psychology at the University of British Columbia. I have worked in the field of rehabilitation for the past 8 years, specializing in counselling persons who have experienced traumatic brain injury, and their families. The faculty advisor for this project is Dr. Larry Cochran (822-6139).

Study: My research study is aimed at better understanding the meaning of recovery from TBI. The information gathered in the study will be included in my PhD dissertation.

Participants: I am seeking volunteers to participate in this research study. The requirements are that she or he has experienced a traumatic brain injury (at 16 years of age or older), is a minimum of 18 years of age, and is able and willing to discuss the injury and experiences before and since the injury occurred.

Time: The study will be in the form of two interviews. These are private interviews with only the participant and researcher present. The location will be arranged to be convenient for the participant. The two interviews will take a total of 3 to 5 hours.

Volunteers are free to withdraw from the study at any time.

For further information please contact:

Researcher: Pippa Lewington

Telephone: (604) 731-1886

APPENDIX B

Study Participant Consent Form¹

Title: What is the meaning of recovery as lived by persons with traumatic brain injury?

Researcher: Pippa Lewington (604) 731-1886

Faculty Advisor: Dr. Larry Cochran (604) 822-6139

The purpose of the study is to understand the meaning of recovery from traumatic brain injury from the perspective of the person who has sustained the injury. Participants are volunteers who agree to attend two private interviews with the researcher. During the first interview we will discuss the participant's life prior to the injury, how the injury occurred and the changes she or he went through from that point until the present. The primary focus will be on what recovery means to the participant. In the second interview, the researcher will present the participant with a written summary of the experiences described in the first interview. The participant will then be invited to revise the summary so that it is as accurate as possible. Additions or deletions can be made at that time.

The identity of the participant will remain confidential. Any identifying features of the story will be changed to protect the participant's privacy. This will be done with the participant's approval in the second interview.

The two interviews will take approximately 3 to 5 hours (2 to 3 hours for the first and 1 to 2 hours for the second).

The researcher will be available to answer any questions regarding the study before, during or after the interviews.

You can withdraw from this study at any time without jeopardy.

I CONSENT to participate in this study and acknowledge receipt of a copy of this form,

Name

Date

¹Approved by The University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects

APPENDIX C

Independent Reviewer Instructions

Please read the transcript of the two interviews with the participant and/or listen to the audio-taped sessions.

1. Was the style of interviewing biased in any way? Was the participant able to tell his or her story without interference or undue influence?

Please read the narrative account of the participant's story.

2. Did the narrative account distort any of the material from the interviews?
3. Did the researcher neglect anything of significance in the narrative account?
4. Does the narrative account accurately portray the intended message of the participant?

Please respond to these questions in written form. You may write as much or as little as you like. If you have any questions, please call me at 731-1886.

Thank you.

Pippa J. Lewington
Ph.D. candidate
Department of Counselling Psychology
University of British Columbia
Vancouver, B.C.

APPENDIX D

Sample Transcript

This transcript is one of seven used in this study. References to the participant's wife have been replaced with W and to his son with S. Some identifying details have been removed to protect the participant's right to confidentiality. Where names have been removed a descriptor has been inserted with <brackets>.

J.G. First Interview August 14/95

P: What I'm doing with the study, J, is I'm looking at sort of the course of recovery for people who have had a brain injury, and kind of getting a sense of what got you to the place that you're at now. That may be recovery, it may seem like it's not recovery, just getting a sense of how you got from there to here. What I find works best is if we start with a little bit about your life before your accident, a sense of who you were and where you were going, what you were expecting your life to be like. And then maybe we'll take a look at how your accident occurred, and some of the injuries that you experienced. And then most of what we'll talk about will be after that, sort of looking at, as best as you can remember, what you went through, what were the things that happened from the time of your accident through to today. Does that sound okay?

J: Yeah.

P: So should we start with kind of life before your accident, and sort of give me a sense of what was going on for you before your accident.

J: Before my accident, I was a respiratory therapist at <a hospital>. And then... actually, it's a 12-hour shift so either you just work days or nights. That's all, days or nights. But then you're given around three to four days duty, right and after four days, you're given five days off. (P: I see) Yeah. But then, on the first day of my day off, usually I just rest, then second day, I go to Portland and work in the hospital, and the third day I still work in the hospital, the fourth day come back and rest, the following day still rest, and get up at 6 a.m. and to work again.

P: Oh, so you were working in both places, in <hospital> and in Portland!

J: Yeah. In fact, sometimes they phone from Portland because the hospital was my phone number then they phone me, "can you work today?" What do you mean? I was just sleeping, you want me to work now? Just drive six hours to work?

P: That's a long commute, isn't it!

J: Oh yes!

P: Why were you working so much, J? Was it because you were trying to get more money? Did you just enjoy working?

J: Two actually, or three. First of all, because I wanted to know the medical benefits of the patients in the states and here. Number two, of course, the money. Number three, I want to experience also the way they [inaudible] in the states. But then I found out in the states, that's where the medical insurance is expensive because everything is being charged to the patient. Even a single, you know, if they open some parts of the

equipment and they make a mistake they just throw it away and charge the patient. And here is all been sterilized, sterilized, sterilized and reuse and reuse and until it won't be used anymore but there the following day, just throw it away. And even the parts that, when we intubate a patient, the following day in the States they just throw it away, even all the parts of the equipment, it all goes in the garbage. But here of course, we sterilize it.

P: You were really getting exposure to both systems to see how different they were and what the different levels of patient care were and that kind of thing. Your training to become a respiratory therapist, was that here in Canada?

J: Yes, here in Canada. And also the medication, between the states and here, its not different, only the trade names different but the generic name like all the chemical names, they're all the same but they just change the canadian trade name and the u.s., that's all. So I'm learning both. So you know right away if somebody prescribes a medication, if he's an american, if he graduated in the states or graduated in canada. And sometimes some people graduate in england and that's different again. You know its good to have that exposure so you won't be ignorant. Right away you know dr. so and so is from england, dr. so and so graduated in the states.

P: So you know what system they're coming from.

J: Yeah, yeah.

P: So you were working a lot at that time and...were you married at that time?

J: Oh yeah. Also it was hard to because specially working 12 hours, like when I come home after my night shift I sleep the whole day and W is at work and S is at school, I don't see them. When they come home in the afternoon, around five or six, its my time to go to work again. I don't find it a good life.

P: You weren't seeing that much of W and S.

J: No, no.

P: W was working at that time.

J: Yeah, she was working too.

P: You were pretty focused on your career at that time.

J: Yeah, yeah.

P: Was there a sense for you of heading in a certain direction? Did you see yourself carrying on this work as a respiratory therapist forever or did you have a sense of planning to do something different? What did you think the future would look like for you at that point?

J: Oh no. There was lots of potential because you could take advanced courses and one day you'll be the head of the...because in respiratory you can be the emergency room respiratory head too. And you can be the ICU respiratory head.

P: And so is that what you were hoping to do was to get the promotion to be in charge of one of those areas.

J: Besides the time is good, just eight hours. Better and the pays good, better. That's one reason but if you're on call if something happens and you can go to work anytime when they wake you up, that's one thing but I was ready for that.

P: That's what you were working towards. And then obviously things changed. Maybe you could tell me a little bit about your accident. How old were you at the time of your

injuries?

J: I'm 52 now, that was 10 years ago so...

P: So 1985, when you were 42. What happened J.?

J: Actually it was March, they still have this, its not snow, dry ice? what is that called?

P: Black ice?

J: Black ice, yeah. My car skidded on black ice and I was on my way to pick up S. from school, that was 2-2:30 in the afternoon, and my car skidded and that's it, that's what happened.

P: So your car skidded and you hit something.

J: Yeah, hit the pole. My car became an L-shape. W said it took them around half an hour to forty-five minutes to get me out of the car, they had to cut the car and everything.

P: You probably don't remember that accident.

J: No, I don't, no.

P: Those would be things people had told you.

J: Yeah and when they brought me to the hospital, < general hospital > ., they didn't even recognize me. My friends didn't recognize me. I was called John Doe.

P: They didn't know who you were.

J: Because I was, my head was all...anyway, the funny thing was, one of my co-workers he boards in our house, he was the one on duty, he didn't recognize me.

P: Because you were so badly injured, around the face, so people didn't recognize you.

J: Yup, of course when W came and S came, why are you here? Oh J. had an accident. Is he the one with the accident? Then my friend you know, this guy is a tough guy, but he cried, gee whiz, how could it happen to a guy like this? Well, it happened, it happened, you know.

P: So he was so upset to find out that that was you that had been injured. That must have been very difficult once people realized who you were, cause you went back to the hospital where you worked and so you were being treat. What happened then J? How long were you in the hospital?

J: Oh I was in the hospital for a week at < general hospital > , no two weeks, and then they moved me to < first rehab hospital > , the rehab at < first rehab hospital > .

P: And were you unconscious for some of that time?

J: 72 hours.

P: When is your first recollection?

J: My first recollection is when I was already at < first rehab hospital > , no I was still at < general hospital > of course. Because of friend of mine who works there too, he's very fond of music so he brought me a tape and even his tape recorder and everything and he played music for me and then gee whiz, it was nice of him you know. Because he knows that I'm fond of music so that's what he did.

P: J. what was going on for you at that time? Were you able to think about what had happened to you? What was your experience at that time, I would guess it was a very confusing time.

J: Very confusing. It was very, very confusing because W said they had to tie me down because I struggle and everything and I kept on saying that I wanted to go to the

washroom but W said I kept saying, I want to pee, I want to pee. They said you can pee, you can go to the washroom because you have the catheter right. That's one reason they tied me down because one day I pulled my catheter and gee whiz, it was just bleeding.

P: So you were a little bit out of control.

J: Yeah.

P: It sounds like part of that stuff you can remember and part of it was just really confusing, not knowing what was going on.

J: Confusing, yeah. And I remember sometimes saying I want to pee, I want to pee and everything but then I remembered that I pulled...but the good thing was that when I was there they didn't have to put me long in the respiratory machine, the ventilator because I was in good shape before because from home when I go to work, I don't drive, I just jog. Return. Jog in the morning, six o'clock, I jogged because I start at 7 and then in the afternoon when I get off at 7 I jog home again.

P: So you were in good physical condition and it sounds like you think that made a difference in terms of...

J: And also being a non-smoker, definitely.

P: So you were able to breathe on your own in spite of the serious injuries.

J: And one thing too, when I was off before, I'd have 5 days off sometimes and I don't go to Portland, I'd go to my self-defense class, so I was in good shape before.

P: So that made a big difference.

J: Oh definitely. Number one is non-smoker, number two in good health. That's the reason why.

P: So you were at < general hospital > for a couple of weeks and then you transferred over the < first rehab hospital > and then what was that experience like?

J: At E.R. it was, that's when they were doing rehab for me right, strengthening my legs, that was a start.

P: So your legs weren't working properly.

J: No because I was in a wheelchair for eight months, would you believe eight months in a wheelchair, yeah, so anyway, after E.R. I think I stayed at E.R. for a month and then after that they moved me to GF Strong and that's where I really strengthened everything and all the rehab and even learned how to walk, learn how to talk and learn how to drive again.

P: So before that you hadn't been able to, well you couldn't walk because you were in a wheelchair, but you couldn't talk as well.

J: Yeah, I can talk but no sense, no sense at all.

P: Did you understand what people were saying to you?

J: I understand them but sometimes when I talk to them I was wondering how come they keep on saying, pardon me, pardon me, come again, come again. That was the reason why, I remember now the reason why. W told me you talk no sense, even S. says its like a telegram, you know if you send a cable right, its all short shortcuts. You talk that way.

P: So people didn't understand. That's must have been very frustrating for you. (J: It is) Specially since you were saying at that time you didn't know why they didn't

understand. Later W explained but at that time you didn't know why people weren't understanding (J: yeah), it sounds like it would have been a very frustrating experience.

J: It was frustrating but anyway whenever they say pardon me, I keep on repeating. And of course my rehab person told me, next time if you say something, think about it first and don't tend to talk too fast because first of all, english is not your language, then you talk too fast, it won't help.

P: So at GF Strong you learned to slow down, put your thoughts together first before you tried to say what you wanted to say.

J: And talk sense, that's what they said.

P: J. do you have a sense of what were the deepest feelings you were experiencing. I'm thinking of when you were at <general hospital>, when you went to E.R., maybe at the beginning of your time and GF Strong, what was going on inside for you?

J: Oh gee whiz, when I was in those hospitals first thing I wanted to do is go back to work. I'd been working before and I wanted to go back to work, that's why part of my rehab was to bring me there with <first rehab company>, to <general hospital>, and somebody was watching me and I'm just helping like a volunteer and helping saying from 10 until 2 in the afternoon. So they have to monitor how I do it.

P: So even though you were in the hospital with a head injury, you had the sense that you wanted to go back to work. That it wasn't, it sounds like it wasn't clear to you at that point that you weren't ready to go back to work.

J: Yeah.

P: There wasn't a sense of this being a big problem, it was just a sense that you wanted to get out of bed and go and work like you were used to doing. What was that like when you knew what you wanted to do but obviously other people weren't letting you do it, they were saying you had to be in hospital and tied down if necessary. What was that like?

J: It was very frustrating of course, it was very frustrating. How come if they can do, I can't do it. But now I realize, gee whiz it too premature. There things that I'm not capable, its premature. Specially I'm thinking, if they let me do that it will be against me because what if the patient dies or anything, it will be against me, even worse because I'll go to jail for that. Now I realize that.

P: How long did it take you to realize that?

J: Oh gee whiz it took me, oh I was still at GF Strong and I wanted to go back to work.

P: So even at GF Strong you wanted to go back.

J: Yeah but it was still too premature. Then when I went home, every morning I had to...cause the hospital is just close to where I live, I could see the hospital and I'd say, one day I'm going to go back to you, keep on saying that.

P: You were really determined.

J: Oh determined, yeah, yeah.

P: And so what sort of things happened at GF Strong? What was that like for you there?

J: Oh it was, it was all different. They taught me how to talk slowly and they taught me the leg exercise and everything and they taught me how to drive again and the taught me how to, they put me in the pool for buoyancy for my legs, everything. That's what they

did.

P: Was that painful for you, to get your legs functioning again?

J: Oh yes of course, its painful, its painful and frustrating, so frustrating.

P: What did you do with that frustration, that sounds like it might even be anger? Was there a way to release it or did it just get stuck inside?

J: They said what are your interests, I said I'm interested in music so in that case why don't you listen to the music or get some tapes and everything. And that's one thing I did and then second, they said what else do you want to do? I want to go back to my photography. So here I go. I went to take a lesson in photography and then I'm happy and later I said, I want to go back to my self-defense course. So I went back to self-defense and that's it, all is done. I'm happy that I did everything.

P: So there were just certain things that you wanted to get back to and doing that made a big difference.

J: Of course, yeah. But workwise, now, even if you pay me double, as respiratory, no thank you, I'm happy. What for?

P: So you wouldn't go back to that life, even if you could.

J: No, not anymore. Its hard for people with head injury, if something happens to the patient, oh I'm sorry, J. had a head injury and that's why the patient died, that's not an excuse. (laughs) What if that's your mother or father, oh sorry Pippa, J. had a head injury, that's why your father died - that's no excuse. First thing you're going to sue me right away, so forget it.

P: So that's a realization you came to back even at GF Strong, you were starting to realize. It must have been a tough decision to come to, to say the injuries are too serious to make it safe to go back to work, I would think that must have been a time of a little bit of turmoil.

J: Oh yeah, turmoil but then I been reading my medical books and gee whiz, I could have been dead now with all my injuries. I could have been dead. I'm still lucky that in spite of this head injury I had...because they had to open my head twice because of the pressure. They have to relieve the pressure, do a craniotomy to me twice.

P: Was that all in the first few months?

J: When I was still at < general hospital > .

P: And so later you were able to go through your medical books and really understand what had happened.

J: Even now I still go back to them. In fact if W says what is this medication, I say wait a sec I'm going to look at my book, I explain to her. As long as you're resourceful and you're willing to learn more, its there.

P: It sounds like your time at GF Strong was a kind of turning point. When you came in you were bound and determined to go back to work and things were going to be OK and by the time you finished your rehab there you had a sense that your life was going to be quite different, that you now didn't expect to go back to work, at least for a long time and that you started to focus differently on some things and it sounds like you had gone through a certain amount of your own emotional turmoil to get to that point.

J: Yeah. And I dreamt that I also go for my volunteer work in the hospital, for handicapped patients, and some of them are in an old age home and I help them and its a

funny thing when I go there. So when are you working next. What do you mean working? I'm not working here, I just come here for volunteer. You mean to say you just come here, yeah just come here to have fun and talk to all these patients because some patients didn't have any family, nobody visits them, right. So when I'm there, we have fun, we take them out for shopping, take me out for picnic and everything so that's a good one.

P: What was that like for you, specially when you first started doing that kind of work to be in that environment where you used to go and be paid to work and now you're going and enjoying it but its in a different way. Was that difficult to be back there but not working?

J: Not really because I'm already used to hospital job and when I was working at the other hospital before, there's some volunteers too working in the giftshop too. Those are all volunteers, those are all retired people.

P: I'm thinking since you'd been in kind of a status position as being a medical professional in the hospital and now you're going in as a volunteer, was there any difficulty for you in that change of position.

J: No, actually, in my case no because I've been used to hospital environment and I been used to all these things. When you go there its funny because some of the old folks they don't even know what they're doing. You can hear all the foul language in their mouth and this and that and I just don't laugh in front of them. I just say excuse me I'm going and then I keep on laughing and laughing. Somebody says to me, how come you're laughing, are you crazy? I say no I'm not crazy its because so and so told me this one and then we both laugh and I say gee whiz, that's really funny so we both laugh together. Because if you laugh in front of these old folks, they think you're crazy, you're nuts and they don't want to talk to you because you're nuts.

P: So you have to be kind of careful.

J: Oh yeah, yeah. Its funny.

P: Just so I have this clear in my mind chronologically, after you came out of GF Strong, did you go back home at that point?

J: Yeah.

P: And then did some of these activities that you're describing start right away or was there a time when you were just at home or doing rehab.

J: No actually, at home, I was under < first rehab company >. Twice a week or three times a week, somebody from < first rehab company > comes to our place and she taught me how to cook and taught me how to talk slowly and everything again, as a rehab.

P: So that was a time of really learning the basics again.

J: From square one again.

P: What was that like for you?

J: It was good because at first, one of my rehab said, you had to write everything down because you forget things. If I want to cook this I have to do this, all the recipe I had to write everything. But then it changed when I went to Lions Gate Hospital (P: Was that afterwards?) Yeah, afterwards. And I'm happier because that's where they told me to get rid of writing, writing because if you forget that's it. Why don't you get something that

can help you, like this beeper here.

P: So instead of having paper everywhere you've got one compact thing to keep track of.

J: It was good there because part of it was the same thing that they did at GF Strong. You should know this maybe because there's a bunch of figures here, like the cow jumps over the, something like that. I think there's a term for that, one of your books. There's a book they look at the book and ask me questions about everything.

P: That was to help you with your thinking and remembering and that kind of stuff.

J: And one of the tests too was like you read a bunch of paragraphs. First there's ten lines, then there's an interruption and then J. can you tell me what you have read. If you're getting better they give half a page, maybe one page you have to read, they say tell me the story after.

P: What that something where you could see progress gradually be able to do a little bit more?

J: Yeah, that helps because first of all she asks me and then after that, why don't you write it down, then after writing down, read me what you wrote down.

P: It sounds like you were really determined to learn these strategies and get better. Sounds like a lot of energy went into that.

J: Yeah, exactly. I don't know what books, I think it was mostly for rehab.

P: For the cognitive stuff?

J: Yeah.

P: And some of those are on the computer as well.

J: That's one thing too. When I was in Lions Gate I did the computers too. It tells you, there's a bunch of sentences right and there's a missing link, complete the missing link, it helped, I liked it, its just like a game but if I think about it its just like a game but its for the better, that's how I think about it.

P: Its fun but its also some thing that's going to help you with remembering and learning.

J: Yeah I noticed that because after my session, there's some people who comes and then, I think they just have a bad attitude because of the rehab testing. Ok we're going to do this thing, that one again, gee whiz I don't like doing that you know. I just didn't tell me, you don't like it. One of these days you'll like what this lady's teaching you because one of these days it'll be for your own good but I cannot tell them. Its up to them.

P: A lot of it has to do with attitude. You could see other people who were more resistant to some of these techniques but it sounds like you were very open to doing anything you could that would help.

J: But on the other hand I'm not accusing them of doing that. I think maybe its still too premature. Maybe it all depends what part of the brain was injured, of course.

P: So timing is important.

J: And of course, what part of the brain was involved. Because as you know, it depends what part of the head was involved in the injury.

P: So what were the things, as a result of your injury, what were the symptoms you had the most difficulty with? What were the things that were really different in your life?

You mentioned, for instance, not remembering things. What other things were a problem after your head injury?

J: Walking, and I get tired easy, because of my leg. I have to concentrate more but now I just let it go now.

P: So its a lot better now, you don't have to think about walking as much.

J: And first of all is acceptance. If you didn't accept it, that's it. That's number one of all is acceptance.

P: And when did acceptance occur for you?

J: Oh gee whiz, after GF Strong there was no acceptance yet and then when I was with <first rehab company> I didn't even accept it yet. It took...and then of course I went to you, to Dr. C.

P: That was after <first rehab company> and after Lions Gate?

J: No, after you I went to Lions Gate.

P: Ok so even after <first rehab company> there wasn't a sense of acceptance.

J: Yeah. First of all I didn't like <first rehab company> because I think it was still premature for me because my rehab person kept on saying you had brain damage. Brain damage. I said, why don't you just call it, you have head injury or you have cognitive deficit. Oh you have brain damage. That's one thing I didn't like with her, with that lady. She was too hard. Of course, for somebody that doesn't know about medicine, that's nothing. Yeah, I'm brain damaged, of course its damaged but sometimes I correct her and tell her why don't you just call it mental deficit or something like that.

P: Something that is more acceptable, particularly at that time. Because you were saying maybe some of this stuff was coming too soon. You weren't ready to hear a term like brain damaged but you could accept that you had some cognitive deficits or you knew you had a head injury but that was lot different than having someone say brain damaged. It sounds like you reacted to that in a negative way.

J: I told her about that, yeah. And that's when W said, I told W, oh geez I don't like the way they treat you when they call you brain damaged, why don't we go somewhere and that when we started with Dr.C. Its more professional, like we're talking professional-wise.

P: So what sort of things promoted the acceptance that you finally came to. What helped you get to that point of being able to accept?

J: Like accepting what happened to me? Well from reading that I thought, gee whiz I could have been worse.

P: You mean when you read your medical text and things and really understood what had happened to you, you realized that things could have been worse.

J: Yeah, it could have been worse. And one thing too I see some people who had head injury when I was with Dr.C. When I go there and some of the people I remember from GF Strong and I said gee whiz, here I am I'm taking the bus, I'm driving sometimes coming here. Look at them, they're still in wheelchairs and they're younger than me. That's one thing too, you know.

P: Exposure to other people who'd had other types of injuries and seeing that it could have been worse. In fact I know some of them too because I've seen them there. The thing too is one day when I saw this guy, oh how are you doing, good. Next question to

me, can you lend me ten dollars please? I said actually I'm just taking the bus and that's why I'm going home now because I'm hungry. Of course I know. And after that I said, gee whiz maybe this guy didn't know what he was doing because he's a head injury too. But of course, ten dollars is ten dollars. I said I don't have any money. I remembered him from GF Strong, he was in a wheelchair.

P: It almost sounds like, as you talked with other people, as you learned about what your injury was and what it could have been, you ended up feeling almost lucky. Is that accurate?

J: Oh of course, yeah. Its true. Not only lucky, very lucky.

P: Sounds like that was part of your own acceptance, to say OK things could have been a lot worse so I'm going to make the best of what I have and decide what's important. Was that an instant realization, one day you woke up and said, I accept my injury, or was it something that happened over a long period of time.

J: Long, long, long period of time. If I tell you it can happened overnight, I'm lying. Its not overnight, no. As you talk to people, as you meet people with an injury and one thing too is... have you heard about the John Simpson Centre?

P: Yes. Did you go there?

J: I go there.

P: What was that like for you to go there?

J: Actually its good because I see some people there that's even worse than me you know and then JJ. said, you know pa, of all of the people who goes to the John Simpson Centre, you are the most normal. I said why? He goes some of the them are...the way they talk, they wear canes and everything, you're the most normal. That's what he told me. In fact one day we're driving with S, S's driving and there's this guy who was with a cane walking and I called him hi Joe. S said do you know him dad, I said yeah, he goes to the John Simpson Centre. That's when S said between you and him, you are the most normal person. And then my nephew, N, you're right, that's right S, uncle is really lucky, look at this guy, he's got the cane and everything and uncle J. can drive and he go back to all these things, he's back to his self defense class. You better believe it, I'm lucky. That's one thing too you know.

P: Sounds like you feel very lucky that you are able to do as much and also you put a lot of determination into making things work for you and doing things like going back to the self-defense and taking up photography and doing the volunteer work. It sounds very difficult to go to a place where you used work and now be a volunteer. For you its given you a lot of pleasure and its worthwhile.

J: I enjoy it. In fact I miss it. W said you have more times with your volunteer work than doing something at home, clean the house. I said well I enjoy it. So what's your schedule today. Oh today I'm going to this place and then what, I'm coming home to cook supper (laughs).

P: It sounds like your schedule is pretty full these days. You still do the volunteer work (J: yeah, yeah) and do you still do the self-defense, take those classes and you go to the John Simpson centre and you prepare dinner.

J: (laughs) Yeah, that's what S says, pa you're not a housewife, you're a housedad. He's right, I enjoy it you know, I enjoy it.

P: I guess you've spent a lot more time with him. (J: Oh, yeah, yeah) Having come through the injury which was a bad thing but it sounds like one of the silver linings was that you spent more time with your son.

J: And with W.

P: And with W. Obviously from what you're saying, your lifestyle changed significantly, before you and W were both working and then after your injury you were home more and it sounds like you've taken over a lot of the domestic things, like you pay the bills, you make the meals, do you do the shopping as well?

J: Exactly, shopping and grocery. Except buying her clothes of course.

P: So she buys her own clothes but other than that...and you mentioned going on holiday with S and things so, it sounds like your whole lifestyle changed a lot after that injury and in some ways there's things you like about that, like having more time with W and S. What was it like for W and S? You had the personal experience of going through your recovery. What was it like, do you think? What was it like to see them having to go through this as well?

J: It was hard for both of them, definitely hard. Yeah. I'm not the same as before, lets face it, I'm not the same as before.

P: So you had changed. What, in terms of not just ability but in other ways as well.

J: Just like thinking and planning at home. Its always W who...if I cannot figure out what to do, I ask W or S. We sit together. What should we do for this. Do you want to listen to my suggestion, Ok, this is my suggestion. Then S says this is better and W says this is better. We talk together.

P: So before you were more of an authority, were you? You were head of the household.

J: Of course, yeah.

P: Whereas now its much more of a consensus, everyone gets together and agrees.

J: Yeah.

P: That sounds like a loss of power for you.

J: Yeah, yeah, definitely a loss of power, yeah.

P: And maybe some loss of independence as well, in terms of being able to make your decision and go. Now you feel like you need to check that its a good decision.

J: Yeah.

P: That sounds like a tough thing, that's been a little harder to live with.

J: Yeah, it is, its hard.

P: Even now, do you find that?

J: Not really because before I make suggestions, first I think, think, think. What does S think of this, what does W think of this, I don't just think of lets do this. There's pros and cons if I do this.

P: So you really sit down and think about it beforehand. So your relationship with S has changed a lot between before your accident and since then. How is it different now?

J: We're closer now.

P: From spending more time together. (J: Yeah) It sounds like he's been very supportive.

J: Yeah, in fact when I went back to self-defense, he said he wanted to go back to self-

defense too because W told him you're getting fat. Look at your dad, your dad's losing weight, he doesn't have the belly because they make him work hard in the gym. He said I think I want to go back to my class, I said sure, anytime. And I'm happy because he's taking it with me.

P: Your role with him is still as his father, but you also have a friend like relationship.

J: Yeah, friends is true you know, I think its better. Its better than I'm the authority, I'm the father, you do this or else, things are not like that now. He's 21.

P: Sounds like you feel more comfortable with that kind of relationship of being equals instead of you having all the power and deciding what to do. And it seems like he has also adapted to the changes in his father.

J: Yeah.

P: And what about your relationship with W, J.? I imagine that changed as well.

J: Yeah.

(End of first side of tape)

P: Whatever you're aware of that was different as a result of your injuries, how your relationship changed. You mentioned they both went through a lot and it sounds like the way that you operate as a family has changed and oftentimes people say that their relationships with their spouse change as well.

J: Actually, she has to plan more than I do these days, she plans more. That's one change that I found, that I accept. She plans more and she decides more than I do.

P: I see. And is that different than it was before your injury (J: Yeah, yeah) Did you used to be the primary planner and decided and so that's kind of a role reversal. Was that tough for you at first?

J: At first it was tough but planning for bills and everything, she should know better because she's an accountant, that's what I'm thinking.

P: So its going with her strengths.

J: Why don't we use her strengths as an accountant so she can figure out what to do with this thing and the managing of this paying bills and grocery.

P: That's a way to make things work as best they can. So where there used to be kind of a hierarchy in your family, now its more equal footing, or maybe even with W with a bit more authority to...

J: Yeah, right, right, more authority.

P: That's right is it that she's a little bit more in charge and you and S are a part of the decision making but she's more likely to do the planning and things like that. Some of the people I've talked to J., talk about spiritual changes that they go through too. For instance, some people didn't have a religion before their injury and afterward they did and some people just say they look at life differently. What's your own sense of how things changed, or if they changed at a spiritual level.

J: Spiritual. In fact I enjoy it more now because I sing in the choir. That's why I enjoy it because I like music and I sing in the choir, in our church choir, so that's changed.

I'm more involved in the church too and the community now, being a member of Knights of Columbus and Lions International. In fact at Lions International they said do you want to be one of the executive, I said no I don't want to be executives, I just want to be good member, that's all. Why? You can think. I said, yeah I can think but I don't want

to get all the headaches. On the executive its hard because there are five executives and you decide...I'm just a good member, ask my opinion and I'll tell you but I don't want be one of the head...

P: You don't want to get caught up in all of that stuff. You want to just be able to go and it sounds like there's a lot of activities involved with the Lions and with the K. of C. What about inside, has there been a change for you how you feel inside about your religion or about your own spirituality?

J: About my religion? No in fact I have more time with my religious thing now, I sing in the choir I go for all the things and help and everything...I have more time for that.

P: It was there before but now you can devote a lot more of your energies to it.

J: That's true, energy. Because before, forget about going to church, I'm sleepy, I've worked 12 hours...but now I wake up and go to church and help. It didn't change but as you said, for some people it changed. Some people didn't have religion before. This I know from the J.S. centre because these people didn't have religion before but its opposite now. Gee whiz they don't even do this before a meal they have to pray and they have to be serious, they're really serious you know, they're really serious.

P: So they really made quite a drastic change. From not having religion to taking it very, very seriously.

J: Very serious, yeah and that I noticed.

P: But you always had a certain faith and you've carried it with you and now you have more time to devote and more energy to put into it. Was that faith important to you in terms of recovery? Was it something you turned to in hard times?

J: Like praying? Oh yeah.

P: Whatever ways. Some people look inward and they kind of find something to hold onto when they're feeling down or hopeless about getting better, about the way things have changed. Was that something that was important in terms of your own recovery?

J: I don't really get your question.

P: I guess what I'm hearing from you that is most important is being involved with K of C and groups like that, more so than for instance, some people will talk about their relationship with God and being able to talk with him or whatever, different religions. For some people a sense that if they hadn't had that connection it would have been much harder. It sounds like its not so much for you.

J: To think of it, ever since my injury I've always been a religious person, just a continuation.

P: It just carries on, its just something that's there.

J: Yeah, its always been there since I was baptized I was already a catholic so its still there. There's nothing new to me. Some people say oh geez you should do this, you should not eat meat on friday because of this and that. Yeah but what about on other days, you do something worse than doing that. That's how I think but I don't tell them this.

P: Right. So you've just found a way that it fits in your life and you're comfortable with it and its maybe not as serious and people who take it on later and develop a religion. You've found a way to be very comfortable with it and its just a part of who you are.

J: Except that now I have more time to spare for my religion now, being involved with K of C because they even put me as one of the...before first I was outside guard and then inside guard and then after two years, they said you want to run for this also I said no I just want to be a good member that's all, enough of these like this. I didn't say enough of these things, I just said I want to be a good member that's all. But J. you're already one of the top brass, I said I'm satisfied as it is you know. I didn't tell them the reason why, you know, if something happens, you'll be one of the first to answer for this you know.

P: You don't need to take on that additional responsibility and headache. You just want to do what you're familiar with and comfortable with and make a contribution in that way.

J: One more question they said why don't you take your fourth degree, I said sure lets go for it. That's easy because first degree, second degree, third degree, you're in the top bracket now, why don't you take your fourth degree. I said sure lets go for it, as long as there's no headache, there's not headache. I should just join the meeting so there's more meetings now because I have the meeting for my third degree, I have meeting for my fourth degree.

P: So those are things that you earn but they don't necessarily mean more responsibility.

J: Yeah, so its fun.

P: Sounds like it keeps you very busy.

J: You better believe it, very busy. In fact today I have volunteer today at the hospital but I phoned them and said I cannot come, I have more important things to do. I didn't say I have more important things to do than help in the hospital I just said I had something. I didn't tell them I'm going to help my friend for her PhD. I didn't tell them that. I said there's something else I have to do which is important. OK next time.

P: Thank you for making it a priority. I appreciate that. Tell me J, do you feel like you've recovered from your brain injury.

J: Recovered? How do you say recovery, how do you define it in that sense?

P: You know I think I'm going to leave it open and ask you what it would mean to you, because I don't know. What would you think of as recovery?

J: In what sense recovery, like thinking, memory...

P: Yeah, all of those things. A sense of finishing with the head injury and just moving on in your life. I guess my question is, is there a point at which one ever recovers from a brain injury? Is over it and carries on with life or is it something that is just always there?

J: Oh no, I get your question now. I still have this memory problem that if I don't think and think and think and concentrate, I tend to forget things. That's one thing.

P: So that's something that's a part of who you are now, you know that your memory is not 100%.

J: Of course, I'm getting old too, I'm 52. That's a good excuse. I tend to be forgetful still.

P: So that's one of the things that just lingers and it sounds like you're not thinking that's going to go away at this point, that that's something that you live with.

J: Yeah, I live with it. And of course its different if I'm 20 years old or 18 years of

course it can improve but to think of it, I'm 52, and damage has been done.

P: So what you can do is what you are doing, which is carry ways to remind yourself. In other words you use strategies to cope with the memories deficits. So I guess what I'm hearing from you is there's certain problems that remain, certain deficits that remain as a result of your injury but for the most part, you have over these years found ways to cope with them so that you're living a life that you're feeling pretty good about.

J: Yeah, in a sense, yes. As I said, acceptance is number one. If there's no acceptance, forget it.

P: We talked about how acceptance built up for you, how you gradually over time got to a point of accepting. Once you had accepted, was that done or do you find that even now you have to sometimes work on acceptance.

J: I always accept it.

P: So once you accepted it, you're done (J: Yup) and its just there and so that doesn't haunt you.

J: Nope, its history. Its history.

P: It sounds like at that point, at the end of that process when you felt like you accepted, it was a turning point.

J: It is! It was, it was, it was.

P: Did you notice that it your life?

J: Yeah, it was.

P: How did it make a difference after?

J: Acceptance? If I'm brown I'm brown, I'll die brown. I was born brown, I'll die brown, that's it.

P: It sounds like emotionally that was a better place. Once you accept who you are or what you're living with, it sounds like that was easier inside to carry on your life (J: Yeah), sounds like it took a lot of pressure off. Is that accurate?

J: That's true, yeah.

P: So that's a point at which you really looked at bringing in good things in your life, doing lots of things that are meaningful. It even seems like you took some things that were of value in your life before your accident, but you hadn't devoted the time to so you were so busy before your accident that even though your family was important and even though some of the other things were important, you didn't have time for them all. And after your accident, they moved up to the top of your priority list and that's where you devote your energies now. So for you there isn't a point of recovery where you can say, ah hah, I've recovered, its like this is an ongoing thing, there's deficits that stay with you as a result of the injury but its more to do with how you have accepted them and adapted your life to still be meaningful.

J: Yeah, still meaningful.

P: Are there any things that we haven't touched on that you think are important in terms of what has helped in your recovery?

J: Can you put it in another question?

P: Yeah, when I think over what we've been talking about J., it seems like some of the things that helped in your recovery were for instance, having a wife and son who were there for you, who cared. Of really devoting yourself to your rehabilitation, to really

learn as much as you could, to be active. It seems like you're happiest when you're busy (J: Yeah), when you know exactly what you have to do and you do it (J: And you accomplish it) then your happy. You accomplish it and say I've done that and you check that off on the calendar. Those things all seem like they've been an important part of your recovery. Is there anything that you can think of that we haven't, that was also important, that we haven't talked about.

J: Not really. Part of my recovery was when they taught me how to cook, I'm still a bad cook, I was a bad cook and I'm still a bad cook, I'll never be a chef (laughs), that's one thing.

P: You can put a mean together but you're not always happy with the results.

J: Exactly because I can never be a chef anyways.

P: You have your strengths but that's not one of them.

J: No, no, no. And my strength is my hobbies, photography, my self-defense course, that's my strength and of course my volunteer work, everything. That's my strength.

P: Those are your strengths, those are the things that give you pleasure and give you a sense of accomplishment and seem worthwhile.

J: And helping all the old folks, make them happy. Then they seem me, oh am I glad to see you today. I said why are you glad to see me, because you're going with us swimming. I say of course, we're going swimming, its good to swim, then we laugh, that's the pleasure of helping. Especially the old folks because think of it, someday I'll be in the same situation.

P: And it would be nice to think that there'd be someone...

J: That's what I think, somebody would help me, I'm good to these guys now, someday I'll be in the same situation I'll be in an old age home, somebody will help me. If not well, I've done my share, I'm still happy. That's how I think.

P: That idea of do unto others.

J: As you want others to do unto you.

P: Exactly. Any things J. that made it harder to get better. You mentioned, I don't know if this is necessarily an obstacle but you mentioned that at < first rehab company > some things came too soon. You weren't ready to hear certain things or to do certain things. Were there any other things that made it harder to get better, to find a life that you were happy with?

J: With < first rehab company > you mean.

P: No with anything. When you think all the way back from the time of your accident right up to today, are there any things that you might think, gee if that hadn't happened I probably would have got better faster or I didn't have to go through such a hard time over such and such. Was there anything like that that you can think of?

J: No, like things could have been faster than this? No I still have that belief that Rome was not built overnight, in a single day, so it takes time. I always have that belief.

P: So even when things seemed awfully slow...

J: Someday.

P: Someday it will happen. So patience was a real virtue in your case

J: (laughs) That's true, yeah.

P: Did those help? We haven't talked that much about it but I would guess there were

some very dark times for you, some real down times. And at those times, when things like that, patience, thinking it will happen, its just going to take time, would that help? What would you do when you were feeling those really down times? What did you do to survive that and to keep going?

J: To survive that I'd do something I really like doing like listening to music. In fact I never liked music like classical, like Chopin, before I never liked it now gee whiz I said if you like music, you have to listen to these people are smart, like Chopin, Beethoven and everything like. People who don't like this have something wrong with their head, because these people are genius.

P: So you have a real appreciation for that music. And when things seemed harder, that by listening to that music, it would be soothing, start to feel a little better.

J: Oh yeah, in fact if I can't go to sleep, I put those nice music, classical music and I wake up, gee whiz my tape is done, 90 minutes is done, fast. And here I am waking up the following day, relaxed and everything, which I like.

P: So you've been very creative in finding the things that help. When you encounter a problem you figure out what you need to do to get past it.

J: Nobody can solve it except yourself unless you go to a psychiatrist but what for? I'm not a cuckoo.

P: So even though your independence was diminished a little bit, you still rely on yourself to solve the problems. If you have a problem, you figure out what would help and you seek it out. It sounds like by taking that attitude, you've created a lot of good things in your world that make it meaningful and happy for you.

J: That's really true, yeah.

P: J. is there anything else that we haven't mentioned today or you want to add?

J: I don't really know. You're the one that knows more than me regards to this thing.

P: As I said I'm not looking for anything specific just a sense of that whole process of recovery from brain injury, the experiences that were important. What I'm going to do is, as I said, I'm going to type up what we've talked about today and then what I do is I put it into kind of a story form so I start at the beginning and go through in order because we didn't always talk about everything in order which is fine. So I'll put it in order...you were going to say something.

J: I was thinking, with all this talking, I'm saying how can P. figure out what I'm talking about and how can she put it in chronological order. That's what you're saying.

P: So that's why what I'll do the best I can I'll put it in order and bring up some of the things that you've talked about today and then what I'd like to do if I could, is meet with you one more time (J: Sure) and I'll show you what I wrote and maybe we can go through it and you might say, this happened before that so I can switch it around and make sure I have things in the right order and make sure that the story seems right for you, that's its accurate. Also there maybe some things that between now and then you might think, oh i should have mentioned such and such, that was important, or this happened at < first rehab company > and that was important, or somebody at gf strong said some things that were important to me. If anything like that comes up, then we can add that in our next meeting. What I hope to have at the end of it is as full a story as possible of your experience.

J: Oh there's one thing I forgot. Good thing you told me about that because, have you heard about speech therapist, her office in the same building as Dr.C., I have undergone that too because of the way I talk too of course. Which is good because there are six of you and one day you'll be the guest speaker and think about what to talk about, you're being taped to and they'll show it too and they correct you.

P: That sounds tough.

J: To me its fun. It all depends. For me I think its for the best and if you see the tape and everything, I thought I was bad but there's people even worse than me. That's the beauty.

P: So then you look at your strengths where before you might have only looked at what you did wrong. When you see other people, you think I was able to do that, they're having trouble but I can do that and you start to realize you have some strengths. That speech therapy sounds like it was important. You mentioned not being able to speak, having to relearn to communicate but then it sounds like with the speech therapist, learning to speak more eloquently, to be understood, to be able to stand up in front of a group of people and be taped.

J: Not taped like this, videotaped.

P: You watch yourself and hear yourself. That's hard to do.

J: Yeah, its hard but for me it was fun but of course some people, english is their language but they can't talk right because of their injury because of their trach and also because of being hit in the face.

P: Like jaw damage and things like that.

J: After all I said, I'm not really bad, english is not my language and I'm still not bad.

P: And of course that makes a big difference, doesn't it, in terms of going out and being involved in other activities, its very important to be able to communicate. That's an area where you were strong and able to handle that. It brings up another thought for me J. you talked about how you changed, there were some changes that occurred as a result of your injury. This part of you that sees the good in things, that says if this is worthwhile, I'll do it, even if its hard and your very motivated and very determined and very positive, is that who you were before your injury as well, is that something that developed after your injury, that part of your personality.

J: Before I was like this. I want to do this because I want to do.

P: So that same sort of thing, you'd want to do something and you were motivated to do it.

J: I want to do this because I want it. But now, of course, but what if I do this instead, what if I do this, like I have time to think more now.

P: So that motivation is the same but now it takes a little bit longer to do it but you carried over the very positive attitude toward challenges.

J: In fact the more challenge, the better for me, the more I think too, yeah.

P: You really thrive on a good challenge, its something that gives you a lot of pleasure.

J: And to think of it, coming here alone. You said did you have a hard time looking for this place. I said no, because this is my second time to come here already.

P: Oh, did you come here once before to see where it was.

J: Yeah because I was not doing anything, how about if I go downtown, take the bus

and I just walk and that's what Pippa said, there's no elevator because its just a story. Oh that's the one.

P: That's what you'll often do so you can relax before you know you're going to go somewhere, you go there first, you make sure you know how to get there, where it is so that today you could get up and know exactly which buses to catch and how long it would take and exactly where you're going. You really plan things out.

J: Planning, its really important, planning. Last sunday, yesterday the Lions, we had this bbq dinner at one of our member's place so my friend said why don't we go with your car, S can drive us. I said yeah he can drive us but why shouldn't we take the bus. We're taking the bus, he said. Why not? I know how to go there. You know how to go, to take the bus. You know how to go there? Yeah because two days ago I was there with my car and I know what bus to take. I just didn't tell him that if you go to a party you eat and you drink and you don't want to have a few drinks and drive. I just didn't tell him this but that's one of my plans too.

P: In the back of your mind you're thinking its better to do it this way.

J: Yeah, just take the bus and forget it, you could be staggering here and there but you don't hurt anybody. But I didn't tell him this because I didn't want to offend him you know. Take the bus I said, its simple.

P: It sounds like people start to rely on you J. to help them with their planning or know when an event is happening. Because you're so organized I would guess that you encounter people who aren't as organized as you are.

J: Yup, disorganized number one is S. He's very disorganized.

P: He hasn't learned that from you.

J: No, because W says S we're leaving in five minutes and you haven't had a shower yet. Oh that will be fast but the whole morning he didn't do anything all he did was fool around with your cousin, do this do that and listen to your music and now five minutes before you didn't have a shower yet. I'll be done in a minute.

P: He just waits till the very last minute. So I guess when you go on your trips he really counts on you to have every organized.

J: Even the hotel and everything and even the highways, its all be planned, its all been mapped. We stop here, this thing from here to here takes eight hours, nine hours drive and then we gas up here. Its all been planned.

P: So he can just sit back because you've done all the planning.

J: He's the one driving. I do the planning, he does the driving. (laughs)

P: OK J. well that seems like a good place to stop, does that seem ok with you. Like I said I really appreciate your taking this time for me.

(END OF FIRST INTERVIEW)

Second Interview October 16/95

P: What I wanted to do was go over with you today what I took out of our last meeting. And just by way of a reminder, what I'm exploring in my study is what it means for you to recover from a brain injury. What are the important factors in getting better. So what I've done is try to take the things that you and I talked about last time and tried to put

them into order. There's a couple of places where I wasn't sure what order things came in so we'll go over that together and as I worked through it certainly some questions came to mind and some reactions so I'll bring those up with you as well so hopefully we can just go through it together and see where we are with it. I will read it and you can follow along (with his copy) and at any moment, just stop me if there's a correction or something else that you want to say and we'll just go through that way. Does that make sense?

J: Sure, yup.

P: "Prior to sustaining a traumatic brain injury, J. was a respiratory therapist at a local hospital. He worked long hours, four days in a row followed by five days off. He would rest on the first day and then drive six hours to Portland where he would work in a hospital there before returning for one day's rest before his next local shift". Ok so far?

J: Yeah, that's it, you really...that's the way.

P: "He did this to earn extra money and to become familiar with both medical systems. He was horrified at the cost to the patient in the U.S.A. Any piece of equipment used is charged to the patient and then thrown away whereas in Canada such equipment would be sterilized over and over again. He became familiar with the different tradenames for medications used in Canada, America, and England".

J: Yeah, that's true.

P: Is it ok so far? (J: Yeah) "J. was married with one son. He was the head of the household and generally the one to make the decisions in the family. He worked 12 hour night shifts. When he returned home his wife would be at work and his son at school. He slept all day and by the time they returned home, he was due back at the hospital. He lived near the hospital so he jogged there and back each day. When he didn't go to Portland to work, he attended martial arts training. He was in good physical condition. He didn't get to see much of his family but there was potential for advancement in his career. He knew he could take advanced courses that would lead to the opportunity to become head of respiratory with the same opportunity in Emergency and Intensive Care Unit. The promotion offered better working hours (eight instead of twelve) and better pay".

J: Yeah.

P: How's that, alright?

J: Excellent.

P: Anything important that I've missed out so far?

J: No, not so far. Its nicely written. I'll tell you when there's...

P: Ok great. "Ten years ago, in March 1985, when J. was 42 years old, he was driving to his son's school to pick him up when he hit a patch of black ice. His car skidded out of control and hit a telephone pole. The vehicle was bent into an L-shape. It took almost 45 minutes for rescue workers to cut through the vehicle and get him out of it. He was rushed to the hospital where he worked but his face was so badly injured that no one recognized him. He was listed as John Doe. Even a co-worker who boarded in J.'s house didn't realize who he was. When J.'s wife and son arrived at the hospital and told his friend and co-worker what had happened, he burst into tears.

J. was unconscious for 72 hours. Twice the doctors had to perform a craniotomy to relieve the pressure. He remained in the hospital for two weeks. He knows he was confused and disoriented because his wife later told him that he had to be tied down. She told him that he kept struggling to get up and demanded to be allowed to go and pee. Prior to being restrained, he pulled out his catheter, causing a lot of bleeding. During this time, he remembers his co-worker bringing in a tape recorder and audiotapes so that J. could listen to music". When I read that J., it was obviously hard to remember back then but do you have any sense of what the music meant to you at that time. Did the music help in any way?

J: Yeah I liked the music because that's the music that I taped. He didn't bring his music, he only brought his recorder because he knows that I like music and sometimes I go to his apartment and we listen to his music and listen to my music and he knows that I like that so what he did was said J. one day, I didn't even ask for it, he brought that here J. why don't you ask your son to bring some of your tapes and listen. It was good. In fact when I was in the hospital W because you can rent a TV right but sometimes the TV gets really monotonous you know so I'd rather turn off the tv and besides you have to pay extra for that. I didn't know before that, you have to pay to me its just OK but it came to the point where I said I'm just wasting my time looking at this nothing you know I might as well do something that I really like, like listening to the music.

P: Sounds like that was very calming for you, very enjoyable. So when you were feeling low or frustrated, if you listened to the music you felt better.

J: Even these days I still do it.

P: Its just something that you really enjoy. OK. "His friend knew how much he loved music. He did not require much time on the ventilator. He attributes his quick recovery to his conditioning and to the fact that he didn't smoke". J. did that apply to other physical injuries, as well as your head injury? Was there other things for you to be recovering from or was it mostly just regaining the ability to breathe.

J: I didn't get what you said.

P: You were saying that because you were in good physical condition at the time of your accident you were able to get off the ventilator more quickly.

J: More quickly, yeah.

P: What about other injuries, did you have other injuries, other than the head injury.

J: My broken legs. There was a screw that was put here and then the thing is it was an emergency and they didn't have the right size of screw so instead of putting for example a six inch screw, they didn't have a six inch screw because I'm a big guy instead of putting a six inch they put a seven or seven and a half. So the problem there was, this I won't forget, every time I turn on my side like that there's something pushing like that, right. That I never forget even when I was in GF Strong, I said gee whiz this is no good. One day I was in GFS and they said one day we have to bring you back, anyway they found the right size and its about time that it should be removed too. They said its temporary anyway. Its just to hold the pin so that's why they put it. So when they took it out, gee whiz what a relief you know. Of course you can feel it you know. I thought there was something there. They didn't tell me about it, that there was something there. I said what's this, of course you cannot complain before. I did not complain before.

They said how come you keep on lying on your right side because I said all the time, because my left side is sore. Its sore. I didn't know that...they said oh time for the screw to come out. I said oh gee whiz that must be the reason why.

P: So it was the wrong sized screw they put in and you were feeling it and how long did you have to wait before they said they'd take it out.

J: Oh around three or four months at least.

P: So you were pretty uncomfortable with that.

J: Of course, of course.

P: And not even realizing what it was.

J: So when they took it off, its ok now.

P: And then when your legs healed, is that when you were able to get out of the wheelchair or was it also getting your brain to get your legs to work?

J: When I get off the wheelchair. Everyday they took me for physiotherapy, for rehab and everything like that and anyway and also I really wanted to get out of the wheelchair because it was a hard thing but when I go to the washroom I can still use the walker and the cane. But then I said one day I'll get rid of this. They put me in a walker, like not right away. For example, you know this, one day they don't wean you right away (P: Its gradual) Gradual. Ok today we'll take your wheelchair for one hour then you use this for one hour. Slowly and then after this walker why don't you use your cane. Slowly and even in GF Strong they did that to everything. Then they turn around and one day they said J. you still like your cane, no, you can have your cane, you can have everything. How about you J. you need a cane. I said no. The more I used the cane, the more I don't get independent. I want to be independent by doing something so they took it out and after that they asked me if I wanted to learn how to drive again and that's the thing that came next. I said sure I'll take that driving lesson again so I took the driving lesson again everything from the start.

P: And that was when you were still at GFS?

J: Yeah, part of my rehab.

P: When you were learning to drive, that was after you had gotten out of the wheelchair.

J: Wheelchair and cane.

P: And the walker and you weren't even using a cane anymore at that point.

J: No more except they were still strengthening my legs because this one is still weak. What they did was there was a pole this high they make you go up and down, up and down, it all depends, maybe put your right leg up first and down with the left and alternate. When you're tired after ten, do the other one again, alternate. Or treadmeters, they keep on increasing the weight, today ten pounds for one week and then 15 pounds, 20 pounds until...

P: Hard work.

J: Oh yeah.

P: It was really important for you to get your mobility back, to get out of that wheelchair. And it was almost like if the cane was there you might use it so you wanted them to take it away.

J: The funny thing is too, I haven't told you this, a year or two years ago and I went to church, we had a meeting for K. of C. and I was using a cane and then one of our top

guys said J. why are you using a cane today and I said because my foot is sore and the doctor said I've got gout. We were kidding and he said J. you must be rich, what do you mean rich, he said gout is the disease of a rich person. I said really and when I went home and I look in my book, of course you have all the caviar and all the good stuff. I said caviar's expensive, I went to Robson, there's a store there that carries caviar, the most expensive one is the Russian caviar, \$98 for a small one and that's already on sale. So anyway my doctor gave me that [inaudible] for gout but I've been taking it but I was reading it and as long as you watch your diet, don't go for those food stuffs and everything so I haven't taken it for around a year now, I didn't take it, goodbye.

P: You done with that. You watch your diet.

J: Yeah, diet. You must be rich. I said what do you mean rich, you should know me, I'm on disability, I'm not working how can I be rich. Yeah but you can still be rich. Then the other guy said yeah J. your not rich in money but you are rich in heart.

P: That's a nice thing to say.

J: Yeah because he called me, how's my buddy J? He's the one who said, you want to be a K. of C.? He said where's your form? I said gee whiz how come its that easy. I said well my dad was a K and my father in law was K, you just ask the right person. Ask and you'll be given. Seek and you will find. Yeah, that's in the bible J. he told me right away. Its funny. He said sure, where's your form, I'm going to sign right away. That fast? Sure. Lots of good things that happened. Of course its a good thing that they are on my side and they are good to me.

P: Oh absolutely. And I thing further on I've got some other questions about the K. just so that I'm clear so I'll ask you some more about that.

J: Ok.

P: "He attributes his quick recovery to his conditioning and to the fact that he didn't smoke". You were saying earlier on that the doctors had to perform a craniotomy to relieve the pressure. Did you have to have brain surgery as well?

J: Oh yeah, of course, first of all was the brain surgery, right. They opened it, that was around 2:00 in the morning because my accident was around 2:30 in the afternoon. This I know after, she received a phone call, Dr. C said oh Mrs. G. we have to open J's head again, why, because there was increased pressure, intracranial pressure, sure just do what you want to do, so they open it again.

P: Something they needed to do to take the pressure off. "J. was transferred to a rehab hospital" Now let me just get clear. How long did you stay at < general hospital > before you got transferred to < first rehab hospital > ?

J: Oh I think I stayed there for at least, I don't remember, because when I was in < general hospital > , its all brain injury, for brain and then after that they put me in the ward that's for anybody. Lets say around four weeks, a month, I'm not sure, roughly a month.

P: A month and then that's when you got transferred to < first rehab hospital > .

J: Yeah and then there another month again.

P: Another month at < first rehab hospital > .

J: The longest was GFS of course.

P: "So about a month later J. was transferred to a rehabilitation hospital. He was in a

wheelchair and the medical staff there began work on strengthening his legs. It was terribly painful and frustrating. He had to do leg exercises and go in the pool for buoyancy. He had also lost the ability to verbalize his thoughts. He understood what was said to him but had difficulty expressing himself to them. It was terribly frustrating because people kept asking him to repeat himself over and over again. He couldn't understand why they didn't know what he was saying. To cope with his feelings, he would calm himself with music". Is there anything else that took place at < first rehab hospital > that we didn't touch on in that description? Was it mostly to work on the physical rehabilitation?

J: Yeah, mostly, every day.

P: Do you remember how you were feeling during that time at < first rehab hospital > ? Was that still a time of a lot of confusion for you or were you more aware of what was happening around you.

J: Oh still confusion. I was even confused when I was in GFS, even confused too you know.

P: So you were mostly doing what people would tell you to do (J: yeah, yeah) but maybe not being really clear about why. (J: no, no)

J: Also I'll tell you something when we come to GFS.

P: OK we're just coming up on that I think. "After one month he was transferred to a different rehabilitation centre where he continued to work on his speech and mobility. He worked on putting his thoughts together before he expressed them". So this is at GFS. (J: yeah) So once again, once you got to GFS, there was that sense of even though you weren't clear about what was happening, other people would tell you what to do and you would do that, trust them that they would work in your best interests. (J: Yeah, yeah) "He also took training to learn to drive again" So as you were saying, that was after you had done a lot of rehabilitation to get your mobility back and also by then were you speaking better, were people able to understand you better when you spoke?

J: Oh actually...

P: Or was that still a problem?

J: Still a problem. Even when I was there because on weekends I'd go home and still have a problem.

P: So you were able to go home on weekends when you were at GFS. You stayed there Monday to Friday and went home on the weekends. (J: yeah, home on the weekends) What was that like to....

J: Oh gee whiz, this I'll tell you. W picked me up at 5:00 right. After breakfast in the morning, this I cannot forget, after breakfast, breakfast around 7 or 8, after breakfast, what do I do, I go down to the lobby and wait for W from 9:00 and then around 11:30 they called for lunch again so we have lunch and then I go back there again.

P: You were so anxious to get home.

J: Yeah, yeah and in between there was rehab because 8 o'clock I wait there and then its rehab at 10 o'clock we have rehab right then we have rehab for an hour and after that its time for lunch, and then after lunch, lets say 12-12:30, what do I do, I go back to the lobby and wait again until 5. Then around 2 I have the rehab for my legs again. (laughs) Now I'm thinking its funny, its funny, I'm not crying but its funny because of my

laughter...its really funny.

P: Plus I mean as you talk about it too J. it must bring up some of the feelings that you had back then when you think about what you were going through and at the time you were saying that you were more confused but now as you look back on it you probably understand more clearly what you were going through and that must have been a very painful time to be away from home and away from work and so its makes sense that you'd be sort of desperate to get home and for W to come and maybe it doesn't make sense at the time but probably you look back and understand why you would...

J: And the thing is if I'm home on the weekend then Sunday night she drives me back, right. Then after breakfast in the morning we got to church 11 till 12 and after I come home from 12 o'clock till 4 or 5 o'clock I'm sitting on my lazyboy waiting for the hour, waiting on the time, how many minutes more, how many seconds, till she drives me back.

P: Its like those were sort of markers for you (J: Uh huh) How did you feel when you knew you had to go back on Sunday? Do you remember how you felt?

J: First of all, I didn't like to go back but then W said are you crazy, even S said are you crazy. You're not a prisoner in there or a prisoner here, why don't you...its for your own good. I was thinking gee whiz, its right. And I had this book about the head injury and everything and about the stages of mental rehab and I thought gee whiz, its takes time. At the same time I keep on reading my book too you know.

P: So part of you just didn't want to go but then as W encouraged you and as you read a bit more you were able to understand why. And it sounds like once you understood a bit better, it was easier to have to go back but before that it must have been very hard to have to leave home and go back there on a Sunday.

J: The funny thing is one of my roommates before in GFS was a funny guy too. He was in a wheelchair and he always needed help and keeps on ringing the bell and as soon as they come, oh can you move me on the side like this, because its sore, he cannot move because he's paralyzed from down here. As soon as the nurse or aide comes out, he rings again. As soon as he goes to bed around 10 or 11, everything 5 minutes or 10 minutes and there here I am, I was really mad but gee whiz look at me I can walk around, I was even luckier than that guy. He can never, never.

P: So once again seeing ways in which you were recovering well and being able to do more than some people could. It some ways that was encouraging for you to see yourself getting better.

J: And to think of it this guy was not even head-injured. He was not in a car accident. He was a biker. I think somebody hit him in the back or he fell from his bike and the spine the thing that...

P: Spinal cord injury.

J: Spinal cord injury. Gee whiz that's even worse you know. I'm still a lucky guy.

P: So how long were you at GFS in total?

J: In total, gee whiz, I spent Christmas there, around six to eight months at least.

P: A long time. Because your accident was in March and you were in hospital for about a month into April and then into May at < first rehab hospital > and then June, July, August, September, October, November, December, you were saying in there for

Christmas so that's at least seven months just to get to Christmas. And then sometime in the new year, was that when you were able to go home?

J: No, not even after New Year. I think January or February, I think.

P: So like you say, a good eight months or more. Its a long time. And the same thing all the way through, you'd be there during the week and you'd go home on the weekends.

J: Yeah, outpatient, yeah.

P: And so when was it in all of that that you were able to take the driving lessons?

J: When I was still there. I was still...

P: So was that towards the end of your time there, probably in the winter of, during the wintertime?

J: No I don't think it was winter no because I wouldn't...I think it was close to fall because the leaves were turning.

P: Sort of like this time of year.

J: Yeah, yeah.

P: What did that mean to you J. to get your license, to be doing the driving again.

J: Oh gee whiz, this I couldn't tell you. When I first drove, two hours driving lessons right, after that I'd get really tired because how tight I hold the steering wheel. If I'm holding your wrist like that gee whiz your circulation wouldn't...

P: Because you are holding so tight, you're just clenching it. Because you were nervous or scared or just concentrating so hard.

J: I don't know the reason why and also I noticed this that before when there's music it gets me distracted right, I don't want any music, nothing at all,

P: You wanted to really focus on what you were doing? (J: yeah) Was it frightening to get back behind the wheel of a car after having been in such a serious accident.

J: Yeah.

P: It must have been tough to do that. And then also you were saying you were still at times confused and its hard to think clearly and it seems like that must have been quite a responsibility to...

J: Talk about confused, I was really confused. You know why? One day we drove some of our luggage to the airport because I was going to the Philippines with S and here we are, there was this guy we were following because he helped us bring some luggage too. I was the one driving, S was here. Then I saw this cop behind me, this mountie, putting his light on, he was driving on the slow lane. What did I do, gee whiz, am I really cuckoo I'm saying to myself, I'm a cuckoo, you know why? He was driving in the slow lane so what I did I wanted to go to the slow lane because I was in the fast lane right so what I did was, what a cuckoo, I passed him for me to go to the slow lane so instead of the other guy getting a ticket, I was the one who got a ticket. Then he said, why did you do that? I said because I wanted to go to the slow lane. You wanted to go to the slow lane all you had to do was slow down and stay behind me, why did you pass me, the guy said right away. I said, I didn't say because of a head something, I said I don't know I was not just thinking. And then S was too mad, you know pa, all you had to do was slow down and stay behind him instead of passing him for him to pass you. I'm thinking what a...

P: Its sounds like one of those things where, for instance when you were learning to drive again and getting your lessons, that when everything goes normally, its ok but its a bit of shock to see an RCMP and the lights going and everything and you think, oh what to do and it sounds like that's when it was harder to think clearly, like what do I do this is a different situation.

J: Yeah, that's true. To let him go first, I had to pass him first to let him go but the thing is now that I think about it, that's really crazy. Even a grade one, what would you do? I don't know if a grade one would know that.

P: It sounds like you felt a little panicky (J: Yeah) and when you panic a little bit its hard to think clearly and now when you think about it its obvious what you could have done but at the time...that sounds like what makes the going back to driving quite challenging for you. (J: Yeah) I'm wondering J. as you talk about, do you feel like you went back to it too soon or you were encouraged to go back too soon to driving. When I think of holding on so tight, it sounds like that was a lot of pressure on you.

J: Yeah, I think it was lots of pressure but then the thing too I was thinking was when I was in GF Strong this I'm thinking now, if I'm in GFS and its covered under medicare because its part of my rehab because if I'm out of GFS to take the driving lessons would cost me.

P: I see. So you needed to do it while you were there, otherwise it would have been too expensive.

J: And to think of it, I wasn't even thinking about that before. Now I think of it and that's the reason why because W said you want to drive, take a driving lesson and get it at GFS. But now I think about it, it was premature, too premature but cost-wise...

P: It made sense in terms of the cost but maybe it was a little bit harder on you because it was a lot of responsibility, a lot of pressure back then. So the main things that happened for you in GFS was first of all getting used to being there five days and going home on weekends. You did physical rehab, you learned to drive again, you got your license back, are those the main things that happened. Are those the main things that happened, was there anything else of importance that happened while you were at GFS?

J: Oh and also when I was at GFS there are floors. I was in third floor. If you are in third floor, they wake you up to have breakfast, wake you up to bath you and everything. Then once you have improved they take you down to the second floor and now you could go to the dining room to have your own breakfast. Before you even have a seating arrangement, its like in school you know. You sit in seat number one and two and three and you eat this, this and this.

P: Was it like being treated like a child in some ways?

J: No, no.

P: Its just that it was more structured.

J: More structured.

P: And then as you got better and more comfortable, you got more independence and you could go where you wanted to go and sit where you wanted to sit and things like that. So over all was your time there a positive experience or was it a very difficult time for you?

J: Oh I think it was a good experience, one of the best rehab in BC and north america.

P: So there was a real sense for you that you were working to get better (J: Yup) That the things that you were doing there would help you get better. I'm thinking too from my perspective as a counsellor J. that you were going through an awful lot emotionally with how drastically your life had changed, was there help in terms of talking about what was going on for you, was there someone to share that with, or a group that you could share that with?

J: In GFS?

P: Yeah.

J: Yeah, we had...yeah.

P: Sort of a group or something where people could talk...

J: Group therapy

P: how they're feeling.

J: Yeah, how they're feeling. First of all there was a group therapy and as soon as you have improved a little bit you have to lecture to these five people to say what you did you did today, you have to talk to them what you did, what you planned for the day, something like that.

P: OK, alright, lets head on then. "He was asked about his interests and he responded with music, photography and self-defense". Now was that when you were still at GFS, I wasn't sure who had asked you about your hobbies and things like that.

J: Oh no that wasn't at GFS.

P: That's after GFS.

J: Yeah, after GFS because nobody asked me about this?

P: So was that one of the <first rehab company> people. That was when you were back home.

J: Yeah, <first rehab company>, yeah.

P: That's the other thing I wanted to ask you. When you finished at GFS and you went home, what was that like to know that you were finished and you were heading home. How were you feeling when...

J: I was still outpatient at GFS and then after GFS, <first rehab company> came in.

P: But when you left GFS was there a sense of graduating, of accomplishing something.

J: It was good to be going home. But then even when I was home, its still depressing because like my rehab comes around 2 in the afternoon, gee whiz I stay bed until around 1 or 1:30. When she comes I get out of bed. Its still depressing too.

P: It seems like it would have been quite hard to go from the structure that you had at GFS where you had to be there for breakfast to at home, as you said you could just stay in bed until 1 o'clock and you didn't have to do anything until the worker came at 2. Did it feel like a bit of a step backwards in some ways.

J: I think so yeah, yeah. Now I have my time I can do anything but then I'm looking forward for her to come so I can, we can do something.

P: So there was this time but you didn't know what to do with it. (J: No) And maybe didn't even feel that motivated to do anything anyways.

J: No that's true, motivation is the word, no motivation at all, no motivation at all.

P: So you just wanted to pull the covers over your head and sleep as much as you could.

(J: yeah) So when you look back on that time J., do you think you were quite depressed?

J: Yes, definitely. That's why, to do this, to sleep until 1 in the afternoon, I sleep at 2 or 3 in the morning.

P: You just stay up most of the night...

J: Watch TV and everything.

P: And then just go to sleep and just sleep until it was time for her to come. And so it was almost like you re-arranged your day so that you'd be with people, you'd be with the worker in the afternoon and then W would come home and S would come home and you'd be with people at night and then you'd sleep when everyone was away. That was a very tough time.

J: Yeah.

P: And so the purpose of the worker asking you about your hobbies was to get you more motivated to do some things and that's where you talked about music and photography and self-defense being interests for you. So how long did it take to get back into doing some things. Was it a long time?

J: With my music I went to my music right away and photography, I went to photography right away.

P: So almost as soon as you were back from GFS you signed up for photography.

J: Yup, my photography and took lessons and my music I'd be listening and everything.

P: Did you take music lessons?

J: No.

P: That was more listening to your own. And I remember you said you expanded your repertoire to listen to more kinds of music.

J: Yeah exactly. Before I liked ? but after I went out of GFS and I was home I liked more classical and jazz.

P: So you tried new things and found out what fit for you.

J: Yeah, like easy jazz because not too many people like jazz. And not too many people like symphony like Chopin. To think of it, they may think who is this, you know. But then I was thinking gee whiz these are the people who likes to hear the people who has got something in here (taps his head) too, you know.

P: So it was worth exploring and finding out if you could enjoy it.

J: And I did.

P: And then with the self-defense, the martial arts, what was that like physically. I mean, here you were, you'd been in a wheelchair for a long time, what was it like going back to that class?

J: Oh, I haven't told you this but my rehab lady before who comes from < first rehab company >, she was on her third dan.

P: That's a level isn't it?

J: Yeah because in karate first of all you become a white belt, then a yellow belt, is 5Q and then after yellow, become an orange, that's 4Q then after orange its green that's third Q and then second Q is blue and then first Q is brown. Then I've got this black belt, you've got this danagan, first dan, second dan, third dan until the eighth dan.

P: She was very advanced then. She was a black belt.

J: Third dan.

P: Third dan of black belt.

J: Oh yeah you better believe it.

P: So did she encourage you then to get back into that.

J: No, she told me about that, she told me what are your hobbies, I told her about this thing and then apparently my Japanese instructor knows her, they know each other, only she's got different style. And then one day she saw me at London Drugs and she said J. congratulations, and I said congratulations for what, Mr. A told me that, because his name is Mr. A told me you went back to dojo, dojo is a club, oh well the reason why is that one day I want to prove because one day you were telling me that its good to go back and now I'm back. Oh gee whiz J., that's good for you. That's one reason.

P: She challenged you a little bit. It sounds like it was hard because you were having trouble motivating yourself but you committed yourself to going back. Did you go twice a week?

J: Three times a week, two and a half hours.

P: Was it hard to get yourself to go or once you knew you were supposed to be there you'd just go.

J: No they have beach practice. We go in December, January in the cold weather, we'd go to near Stanley Park and then we'd jog there and then we'd do our martial arts for two hours in the cold weather and then after that you'd jump in the cold water. That's discipline.

P: So you did that.

J: Before, not this year.

P: Physically were you able to go back to the same level? (J: Oh, no, no) Or were you having to catch up?

J: No I had to go back from number one again.

P: So you started right from the beginning. (J: From the beginning, yeah) And how were your legs.

J: Its getting stronger now but there's still one technique that's hard for me.

P: Was that frustrating to know what you could accomplish before and then when you went back to find that you had to start from the beginning.

J: No, actually not because I was just a beginner and then here I am, when these higher belts, like green, they do their thing and I followed them and they're surprised, how come this beginner is doing all this thing. The Japanese instructor says that's OK J. can do that with you, he knows. They were wondering how come this guy is a beginner and he knows what we are doing.

P: So you had an advantage on them because you knew more than the level you were working at. "So he expanded his repertoire of music to include classical" and I should put jazz there too (J: yup) "signed up for a course in photography, and returned to self-defense class. His son decided to join him in the latter activity. He also started to do volunteer work at the hospital he formerly worked in. He helped elderly patients by talking to them and taking them out on field trips". Was this all happening around the same time J, you're back at home, you've got the < first rehab company > worker coming in, you're back at self-defense, expanding your repertoire of music, was it around then that you went to the hospital to do the volunteer work?

J: I was already doing that before but this expanded more when I was with you and Dr.

C. because Dr. C told me oh you like that, you should go to < small hospital > , go to Mrs. M. He gave me the address so I went there to < small hospital > .

P: So you were doing more of it.

J: Through you, yeah.

P: So if I've got my timing right, your accident was in March of '85 and basically for a year you were in in-patient recovery and GF Strong and so that takes us to March of '86 and it was '86-'87 when you were getting the < first rehab company > service and...

J: And then after < first rehab company > that's when we went to you, to Dr.C. and you.

P: And that was what, maybe 1987, 1988.

J: Oh, late of '87, something like that.

P: So you'd been doing a little bit of the volunteer work but once you started at Dr. C's that's when you started doing it more formally and more of it. (J: Yup) And the way you described it earlier, that sounded like a positive thing for you, that's a kind of work that you really enjoy, giving you time to be with patients where you hadn't been able to do that. "This activity gave J. immense pleasure because he understood the needs of the patients and now he could take the time to talk with them and contribute to their quality of life. Some of the things they said made him laugh and laugh although he was always careful not to laugh in front of them so they wouldn't be offended.

During this time, J. just wanted to return to work. The extent of his injuries wasn't clear to him. He just wanted to go back to work and it was frustrating that he wasn't permitted to do so. Even after he left the rehabilitation centre and returned home, he would look out the window to the hospital and vow to return to work there. He was determined". Now do I have this in the right order in terms of time?

J: Yeah.

P: You were with < first rehab company > around 1986 but by the time you'd come to see us, that wasn't going to happen (return to work)

J: I extended my volunteer to more areas.

P: So then you were more committed to your volunteer work because you'd be able let go of the idea of returning to work, you'd finished with that. (J: Yup) "He was directed to a rehabilitation service which provided a worker two or three times per week. She would come to the house and help J. work on his speech and his daily living skills. He worked on household chores such as cooking and shopping. It was like learning everything from square one again. To manage his memory problems, he was instructed to write down everything he needed to remember. For the first time in his rehabilitation, J. encountered the difficulty of working with a person he did not like".

J: That's true.

P: Was that the first time? I know you mentioned she wasn't someone that you really liked that well but other than that had you tended to get along pretty well with people.

J: Yeah, I think now the reason was it was still too premature too that time. Because I told her that she always called me brain damaged, right.

P: "She referred to him as brain damaged. He understood the truth of it but preferred terms such as head injury or cognitive deficits". So part of it was she wasn't respecting your desire not to be referred to as brain damaged.

J: Yeah, and as I told you it also depends on the education of your patient or your client. Its very important.

P: So she wasn't treating you with the kind of respect that you were entitled to and its sounds like as a result of that you didn't respect her very much in some ways.

J: I respected her in some ways, as a lady and of course in her martial arts and everything but aside from that, from her finesse of saying things, no.

P: She was a little bit hard on you in that sense, that hurt a bit. Do you remember how long you stayed with the < first rehab company > service?

J: Months maybe, not even a year, because I was not happy.

P: "He and his wife decided to switch services, hoping to find something more professional". How did you and W go about finding the services. That was time when less was known about brain injury and there fewer services, how did you and W find the different services? Did somebody at ICBC direct you to them?

J: Yeah I think J.

P: So she would tell you who's out there and then you would make the choice about what to do. "They discovered a community-based rehabilitation service in the city which J. attended twice per week". And I was trying to remember how long...you did some cognitive rehab as well as some counselling.

J: Was that with you?

P: Yeah, that's right. And then you were there for what, two or three years?

J: At least, at least.

P: You started by going more often like twice a week and then once a week and then after a while less often than that. (J: Yeah, yeah) "There he saw other people with injuries that were worse than his. He encountered people younger than him who were still in wheelchairs. He was able to travel by bus and even drive to his appointments. Others relied on the Handidart. He began to feel very lucky. He started attending a social centre for people with brain injuries". Once again, how did you come about finding out about the JSC? Was that the same thing, through ICBC or maybe through Dr. C. or < first rehab company > .

J: I think it was through Dr. C. Because the first thing they had was far, far away and then this one here, they have their own building now.

P: And was that something that you wanted to do? Some people don't want to go to the centre because they say they don't have a head injury or they don't want to be with other people with a head injury, what was it like for you when you heard about the centre, did you want to go or not want to go?

J: I said give it a try first. I like it because, of course it was not the whole day, you go there from 10 until 2 that's all. It was ok and we'd go and all the things we'd do, nice things and trips. I like it.

P: So it was fun. Nice people, you were doing things.

J: Nice people yeah.

P: It really seems like, as we've talked about some of your experiences, part of what you did was try and keep an open mind to things and say ok let me try it and if it works, great and if not we'll try something else.

J: Yeah, and in fact there's some people there from < first rehab company > that

brought some of their clients and I said gee whiz am I ever lucky, look at these people here they're even accompanied by someone from < first rehab company > just to come here and here I am I just come here by taking the bus.

P: You were able to do a lot more independently than a lot of the people that you were seeing. So that was when you started to feel lucky about the way that things have turned out. "His son looked around him and told his father that he was the most normal one there. He saw people with more severe communication and mobility problems. Later when he was in the car with his son and nephew he saw a friend from the centre and J.'s nephew commented on how lucky his uncle was compared to some of these people. He said that the fact that his uncle had returned to self-defense class was evidence of this". What was it like to hear that from your nephew to say, here's his uncle who's back in martial arts, what was that like?

J: (laughs) I was calling this guy, I said hi and he said you know that guy, he was walking with a cane and I said yeah he goes to the same centre, gee whiz are you ever lucky uncle. I said why, look at you, you're driving us, me and S and this guy and his cane and he doesn't even recognize you and you're back to your self-defense. Are you ever lucky. (laughs)

P: The other thing that struck me is that on the one hand you're feeling quite fortunate compared to other people but I also wonder about the part of you that still felt like you'd had a tough time. I think we're all entitled to a little bit of self-pity sometimes and I'm wondering about, were you allowed to feel sorry for yourself, was that something that you allowed for yourself?

J: What do you mean sorry for myself?

P: Even if somebody else is in a worse situation, sometimes we just feel lousy about what has happened to us or what's going on and I wondered if that was allowed to happen for you. Did you ever just feel crummy that even though other people were worse, you still had to struggle in some ways and that's hard.

J: I didn't get your question.

P: A lot of what we focused on is the fact that you consider yourself quite lucky and your son and your nephew could identify ways in which you were a lot better off than other people. But what about the other side? What about the part of you that felt hurt or sorry for yourself?

J: Because of what happened to me?

P: Yeah, because you'd still be hurt even if you were better than them, you'd been hurt, you'd been in hospital, you'd lost your job, a lot of bad things had happened and I wondered if it was OK for you to feel that way sometimes.

J: Sometimes but on a scale of 10, maybe just one out of 10.

P: So it just didn't feel that for you. You were just feeling fortunate.

J: Yeah on a scale of 10 just 1%, 9% I'm good, I'm ok'.

P: And it sounds like the worst of it was when you got home from GFS and it was like the structure is gone and what am I going to do and once you got yourself focused, then you were busy doing thing and more able to identify feeling lucky. "J. joined the Knights of Columbus and the Lions International". Is this the right time or did this happen later or sooner, when did you join those two groups.

J: That's the right time, yes.

P: So this would be during the time you were at Dr.C's.

J: Oh, after, after.

P: After that, OK. And then I think you've already answered one of my questions and that was why. Didn't you say that your father had been a member of the K of C.

J: K of C and the Lions. My father was K of C and my father in law was a Lion.

P: So this was following your family's tradition.

J: Not really, its just that I'd heard about it but I didn't want to see who should I approach. And one thing to about the Lions international, when I was with F. hospital I was there one day, as Dr. C said, then admit some of the Lions and they were having some kind of affair or something for the patients and then somebody asked, one of the old guys, would you like to join the Lions? I said what are you doing, oh we're donating something to all of these patients, entertaining them and I said sure, why not. In that time he was my friend and he was my sponsor too.

P: I see, so you had to be sponsored into K of C and the Lions Club (J: Yeah) So that was just another thing when you thought about what you wanted to do with your life, here's a couple of different groups that do good work and that you'd like to be a part of and that connect you with your church and your community and so that was the motivation behind it. Ok. "He became more involved with the church and community than he had ever had time for prior to his injury. He joined the church choir". Now is that true that you joined it or were you already a part of it before.

J: No.

P: Ok so you joined the choir and that was you were saying, mostly for the music, (J: yeah) that you loved the music and it was a way to stay connected with something that you really liked. "His spirituality didn't change. Rather, he found he had the time to get more actively involved. At the John Simpson Centre, he met people who found a religion after their injury and who were really, really serious about it. In contrast, J. was always a religious person but his role in church activities had increased. He found a comfort zone in that commitment. He felt pressure from others to be involved in the executive committee of the Lions Club but has turned down the offer in favour of being a member in good standing. He didn't want all the headaches". And I wasn't sure when you were saying all the headaches, would that just be all the normal kind of politics that happen in any club (J: oh yeah, definitely). It wasn't so much not feeling able to do it...

J: No, no I can do it, I can do it.

P: Its just like, why bother.

J: Why bother you know.

P: You're in this to enjoy yourself and contribute, not to deal with all the bad stuff, I see. Now I wasn't sure in what year he attended a rehab program through one of the hospitals. So that would be Lions Gate. When would that be? Are we into the '90's at this point J?

J: Yeah, I think so, yeah.

P: Probably around 1990, 1991, 1992 somewhere in there.

J: yeah it was also true ICBC decided that because of these guys, he's got his PhD but I don't know in what and then he put some probe in here (points to jaw) for my listening

and my understanding, that's part of it too.

P: That's what drew you to the hospital in the first place (J: yeah) and then it turned out they had a program that you could get involved with to do more things.

J: Yeah and he was writing a thesis or studying something, its not a good word but I was one of the guinea pigs for that.

P: He was doing research and you became a research participant so that's why you got brought into it. I see. So it wasn't even so much that you were looking for another program, another rehab program it was more that you became involved in it through some research. "There he was instructed to use an electronic diary which he found efficient and reliable for keeping track of information and commitments. In the program the participants worked on a lot of cognitive retraining exercises. A lot of them complained about it but J. believed it was all for his own good. He also decided you can't rush it. If its premature you couldn't make people appreciate it. They'd get there when they were ready. And it depended on the type of injury too because each of is different. J. finished this program in 19??". How long was that program, just a few weeks, a few months?

J: Oh no, its at least two to three months.

P: Basically, since then between the early '90's and now, it sounds like you've been doing all of those things that you set up. Doing your volunteer work, being a member of the L club and K of C, is there anything else that you've done in that time?

J: I think that's all that I've done

P: So the Lions Gate program was the end of rehab for you. (J: Yeah) Since then you've been living your life and setting things up in a way that hopefully makes you happy. (J: Yeah) "Upon reflection, J. says that a turning point occurred for him when he was able to review his medical textbooks and realized that he could have died or been more severely disabled. At that point he felt lucky and accepted responsibility for his own recovery". Is that true? I didn't know if you'd actually said that or if I was drawing that out (J: Oh yeah, yeah). It sounded like once you realized that things could have been worse, you felt better able to take some charge and want to get better and adapt.

J: It could have been worse if little bit of this thing, like reading my book, just tiny bit of this thing had happened you know, it would have been worse.

P: So really looking at what you had rather than what you'd lost allowed you to move on. "If he had one criticism of the treatment he received, it is that some of it was premature".

J: Yeah, that's true.

P: In other words there's times where you could have gotten more out of it if it hadn't come too soon, is that right? Some of the work you were doing with <first rehab company> where there was a sense of it being too soon or the driving perhaps, although there is a reason for that but just a sense that you were maybe rushed through a little bit.

J: Yeah, rushed through.

P: Right now as you look back on it, it seems like you are able to know that. At the time would you have been able to say its too soon?

J: No because its there, they give it to be, I have nothing to do, lets go for it.

P: Its only after when you've done it that you think, ah now I would have been more

ready to do it rather than then. (J: yeah) Something in hindsight that makes sense. "J. sees the challenges and the rewards in his life following TBI. He knows that he lost a lot of power, authority and independence. Family meetings are now held so that J. can make suggestions and then his wife and son propose alternate ideas. He relies on their input for his decision-making. He has to do a lot of planning in advance of an event. For instance, he may need to map out the bus route or even visit the new location once before the actual day he has to be there".

J: How true.

P: "He still has memory problems although at 52 he thinks this could attributed in part to the natural aging process. He's not as young as he used to be. Perhaps the hardest thing to talk about is not so much the knowledge that he is not the same person he used to be, but that it has been hard on his family". (J: mmm hmmm)

P: We didn't actually talk that much J. about the process of recovery for your family but I get the sense that you all did this journey together and that you worked out problems along the way and that its been on each one of you.

J: Oh yeah, hard on them too, hard on them.

P: A sense too of things getting better gradually in time and finding a way to deal with all the changes that you went through. (J: yeah) "J. acknowledges that by necessity, he has learned and applies great organizational skills. He knows where he has to go, how and when to get there, and what comes next. He's able to successfully juggle a busy schedule this way. He's happy with his life and his interests. He wouldn't go back to work even if he was paid double. He understands now that he is not competent to handle the life and death responsibilities he had prior to his injury. He no longer misses it". I'm not sure, is that true that you no longer miss it.

J: No, my work? No.

P: You don't miss it anymore.

J: No. Never. Forget it.

P: Its like a chapter that's been closed. Something in the past.

J: Leave it to the young kids.

P: Like let them take those responsibilities. "His son calls him a housedad because J. does all the chores around the home and he enjoys it. He prepares most of the meals although he admits he still not a great chef. He spends a lot more time with his wife and son now. The relationship with his son, which used to be an authoritarian one, has now turned into a close friendship. In the summer they took a driving holiday together and had a great time. J. believes that acceptance, although a long process, was the turning point. Once achieved, there's was nothing left to haunt him. The pressure was off. Its history". And then I quoted you "If there is not acceptance, forget it."

J: Yeah. Everything, good.

P: Is there anything that is obviously missing J. Does it feel like this has captured, I mean obviously we've added some things today and I'll add that into the story so that the final story will be more than what you are holding right not, does it feel like we've captured the essence of what you've been through.

J: I think yeah, everything is in here, yeah, it was to the point cause it was recorded and everything.

P: I'll make those changes and one of the things that I wanted to check with you, I just jotted down as I was reading this, there was a couple of things that struck me as key. One of the things that I'm looking for as I go through this to understand it is, what are important events or experiences that help one move through recovery to put brain injury in the past, to move on with life. I guess the biggest one that I heard from you was acceptance, that your attitude makes a big difference, you've got to accept what is (J: Yeah) and find a way to move on and that if you have a positive attitude, you're more likely to succeed at that.

J: Definitely.

P: And you met a lot of people along the way that didn't have that, who had a very negative attitude and who seemed to struggle more in terms of recovery (J: Yeah) Rehabilitation seemed like it played a big part as well, that you did a lot of rehab and that it was essential to getting better but that also sometimes it was premature.

J: Some was premature, some.

P: Parts of some programs where things just came before you were actually ready to fully take advantage of him.

J: Its hard because you cannot ask somebody with a head injury, are you ready for this. Of course they'll say sure. Like me before, are you ready to do this, sure but...

P: And that's a real dilemma that comes up.

J: Exactly yeah.

P: I've talked to other people who said they wanted so badly to do something but they know it would have been absolutely the worst thing if they'd been allowed to. The best thing someone could do was say no which is what happened and so as you say, its hard to know at the time what is best but when you look back on it, that's one of the things that came out. Another turning point for you seemed to be reading your medical texts, making sense of what had happened to you. Once you could make sense of it and seen how things could have been worse then you felt a lot more motivated and lucky to have survived. (J: Yeah) Family seems important (J: Oh yeah) People for instance who don't have family or who's family are broken up and not close, it seems like have W and S in your life was pretty important (J: Yeah) having somewhere to go on the weekends from GFS. And your hobbies and interests, I think of some of our discussions about your photography, it seems like those are the things that have brought a lot of quality into your life, things that you always enjoyed but maybe you didn't have the time for prior to your injury.

J: Yeah, in fact, about my photography, until my injury I was just taking pictures for...but now its got to be something. As I said, people said its an expensive hobby, I said why. Now I know because out of 36 exposures, 30 are garbage, maybe just 3 or 4 are good. Really an expensive hobby. And my instructor told me, if you want a good picture, bring it to Robson, this Customphoto and they know me there now. They say here comes trouble, I said what do you mean, because you want this one to be done this way, of course there's always a change you know, you want f stop of this area, f stop minus one, f stop minus two, f stop plus 3 on this side, that's impossible, what do you mean its impossible, it can be done. Well I'm paying so it can be done, do it. Oh oh, here comes trouble again.

P: Well it seems like the difference between before and now is that your photography is an art now. Before you would record a few things but not its an art. That whole idea about a roll of 36 you might get 3 or 4 good ones, because you've turned it into an art and that's something you've developed over time.

J: Its funny because I tell S and my friends, not bad for an amateur, what do you mean amateur, that's a pro. (Laughs) And then I laugh. To me I'm still an amateur because if I don't know I ask my instructor, I go to him, hey G, when we go for coffee he knows right away that I have problems because coffee...

P: That's the signal is it?

J: Yeah, yeah. Even now when I go to the Bay, and his co workers see me oh, G. is not in until 2 this afternoon, oh G is in the coffee shop having coffee right now. They know me now which is good.

P: You've built that up over time. I've got one last question I might ask of you and its a hard one to answer, I don't know if you can...I'm wondering, does one ever recover from brain injury?

J: Does one ever recover?

P: Have you recovered from brain injury?

J: Like ah, what...is it anatomically.

P: No just in terms of life, in terms of living your life. The term recovery means return to original level of functioning but I think we also think of it as just getting better. So that's what makes it a tough question.

J: It is yeah. Anatomically of course, no!

P: Day to day living?

J: Day to day living, yes.

P: I got a sense as I was putting this together and thinking about the things that you talked about that you've kind of finished with brain injury. Its something that happened to you in the past, you've learned systems, you keep track of things and by doing that, you are living your life, you have things to do you have places to go and even though you have sustained a brain injury in the past, its not something you live with everyday. Its not part of your identity.

J: Oh no, no. J. you're a brain injury, no, forget it. He may have a brain injury even worse than me. That's why I said I enjoy taking the bus because I see, when I came here, I have a head injury and these people even...I might be wrong because some people say oh he's normal but...

P: There's something going on for everybody...there's always stuff that's hidden.

Is there anything else J., anything that I've missed that...

J: No, this was nicely written and everything was nicely written.

P: As I said I'll take what I've taped here and I'll transcribe it and I'm going to revise that story because there's things that we talked about that will expand that and where I'll correct the order things came in so the final version of that will look a little different than that one... (J: OK) ...bit more accurate.

(END OF SECOND INTERVIEW)