

**The Lived Experience and Meaningful Construction of
Traumatic Brain Injury
From the Perspectives of
The Survivor, The Family and The Treatment Professional**

by

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Abstract

This study presents a revelatory case study which draws on phenomenological constructs to explore the lived experience of perceiving and meaningfully constructing traumatic brain injury from the perspectives of a survivor, a family member, and a treatment professional working with the survivor. During in-depth, individual interviews, the participants shared their experiences and described the processes through which they came to understand and make sense of the survivor's traumatic brain injury (TBI), the impact it had on the survivor, as well as their relationships with the survivor. The interviews were then transcribed and analysed using Collaizi's (1978) method of phenomenological analysis. A number of themes emerged which appeared to be central to the processes of understanding and making sense of this TBI for these individuals. These included: the sense of recovery from TBI as a process; the role of awareness in coping with, and adjusting to TBI; the importance of spirituality and optimism in the recovery process; the importance of collaborative goal setting and client-centred rehabilitation.

The survivor who participated in this study assessed his recovery as very good, and his family member, and the rehabilitation professional interviewed for this study reinforced this opinion. Furthermore, the survivor described a sense of having "found himself" through his rehabilitation and recovery experience, and described a sense of satisfaction and meaning in his life which he attributed to his recovery experience. There was a consensus among the individuals who participated in this study regarding appropriate and meaningful goals and priorities. These findings indicate that in this case a client centred approach to rehabilitation was extremely effective.

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CHAPTER I

Introduction

In the province of British Columbia, 6,000 individuals sustain a traumatic brain injury (TBI) annually. Of these, 600 require lifetime support (Conn, cited in Lewington (1996), p.1).

Traumatic brain injury (TBI) refers to any brain or brain stem injury causing damage or dysfunction to any tissue of the brain where there has been sudden impact or contact with the skull bone. The resulting trauma can be mild, apparently temporary (as in mild confusion and disorientation), yet still result in subtle chronic dysfunction. Trauma can be severe resulting in death, coma, or devastating chronic disability. Traumatic brain injury is inevitably disruptive to everyday function, often disabling in its effects on the learning processes and seems to result in social isolation (Mann, Chan, Connell & Unander, 1988, p. 21)

Traumatic brain injury occurs two to three times more frequently in males than in females and onset is most frequently between the ages of 15 and 29 (Rimel, Jane & Bond, 1990).

Typically, individuals who sustain a traumatic brain injury experience a wide range of impairments in physical, intellectual, cognitive, social, and emotional functioning (Sbordone, 1984). These include motor and sensory impairment, perceptual impairment, pain syndromes, communication disabilities, cognitive impairment, emotional lability, and changes in personality and mood. Cognitive impairments may include distractibility, rigid thinking, impaired problem solving, decreased social consciousness, impulsiveness, and perseveration. Changes in personality and mood may manifest in flat affect, decreased initiation, feelings of depression, guilt, anxiety, helplessness and hopelessness (Bennett, 1989; Griffiths, 1983).

Sbordone (1984) suggests that injuries involving bruising or laceration of the scalp, face and neck are classified as minor. Those involving concussion, skull fracture, or intercranial haemorrhage are classified as major. The severity of TBI may therefore be conceptualized as existing on a continuum, with mild or minor brain trauma at one end and severe brain trauma at the other. Bennett (1989) cautions that these diagnostic categories are essentially medical and therefore do not accurately reflect functional physical, cognitive and emotional impairment or the accompanying sense of psychic loss, which may result from a particular injury.

Traumatic brain injury has a profound impact on the developmental tasks associated with young adulthood, namely: " (1) selecting a mate; (2) learning to live with a marriage partner; (3) starting a family; (4) establishing an occupation; (5) finding a congenial social group" (Havinghurst, cited in Stevens-Long & Commons (1992), p. 135). Miller (1991) notes deficits in awareness frequently result in the development of an egocentric perspective, wherein the survivor fails to perceive others as distinct personalities with needs and desires of their own. This loss of empathic sensitivity may preclude genuine expressions of affection, leading to problems with relationships in general and intimate relationships in particular. TBI survivors who are parents may become withdrawn and detached, moody and volatile, or strange and delusional. Some TBI survivors who are parents compete with their children for their spouse's attention, or malign the child whose functional abilities begin to meet or exceed their own (Urbach & Culbert, 1991). Many of the changes in cognition, personality and behaviour, which commonly result from TBI, are inconsistent with successful employment. Even if cognitive abilities remain intact, emotional and psychosocial factors may impede a return to work (Miller, 1992).

Significant others are also affected by the experience of TBI. For example, parents of TBI survivors may be compelled to resume an active parenting role at a time in their lives when they thought their children would be independent.

The spouse of a TBI survivor may resent changes necessitated by the injury and find the dependency demonstrated by his/ her mate intolerable, yet feel unable to leave the marriage for fear of social condemnation (Miller, 1991). "Wives often feel as if they suddenly have another child, and at the same time they have lost the man they were in love with. They are grieving him, but nobody on the outside understands" (Moore, Stambrook & Peters, 1992, p.465).

TBI survivors and their families are faced with myriad losses arising out of the trauma of the injury itself and the adjustment necessitated by physical, cognitive, and emotional sequelae of the injury. Prigatano (1994) suggests that the fundamental issue, with which survivors and their families must engage, in the rehabilitation process, is that of lost normality. Lost normality is described as "primarily the problem of dealing with the changes from a pre-injury state to a post-injury state. . .this includes coping with the hard reality that certain higher cerebral functions may be changed permanently, and the patient may only partially recognize and understand the changes"(p. 94). Prigatano emphasizes the importance of helping survivors, families, and rehabilitation professionals better understand the nature of these problems. Lezak (1986) reinforces this view when identifying ways in which professionals may contribute to unrealistic expectations for recovery on the part of families of TBI survivors.

When they (experienced clinicians) use the word recovery in talking to the family, they really mean improvement, but rarely spell this out. Lay people tend to equate recovery

with return to normal, since little in their experience of other accidents or illnesses leads them to expect permanent change (p.243).

"Traumatic brain injury is a catastrophic life event that permanently changes a person and the family system in which he or she exists" (Kay & Cavallo, 1991. p.121). Given the complex array of physical, cognitive, emotional, and psychosocial changes which can result from TBI (Lezak, 1978; Prigatano & Fordyce, 1986), and the resultant adjustment issues facing the family (Kay & Cavallo, 1991; Williams, 1991), the course of rehabilitation and recovery is a complicated one for both the TBI survivor and for the family.

Facilitating recovery from TBI is a complex rehabilitation enterprise. This is related to a number of factors specific to the injury itself, the survivor, the family, and the treatment professionals involved (Fordyce & Roueche, 1986; Prigatano, 1986; Zarski, DePompei & Zook, 1988). These factors may interact in a variety of ways which determine the direction, progress, and ultimately the outcome of rehabilitation (Lezak, 1986; Maitz & Sachs, 1995; Rosenthal & Young, 1988).

Statement of the Problem

One of the most critical factors influencing the course and outcome of rehabilitation from TBI appears to be perception of injury. This involves the identification and prioritization of issues/impairments which are problematic for the survivor and therefore require treatment intervention. Rehabilitation goals and priorities are established in response to perception of injury; however, these may vary depending upon whose perception of injury is utilized in the determination of these goals and priorities. Clinically, there may be an understanding that some compromise is required to ensure that survivor, family and professional concerns are addressed

in the rehabilitation process. However the particulars of the compromise, the negotiation through which it is reached, or the rationale for making that compromise, are rarely articulated. As a result, it is unclear whose perception of injury is being utilized in the determination of rehabilitation goals and priorities. This may have implications for the survivor's, and indeed the family's sense of power and control in the rehabilitation process (Maitz & Sachs, 1995). This may influence their level of investment in the rehabilitation process, which in turn may have a significant impact on rehabilitation outcomes (Prigatano, 1995).

It appears that perceptions of injury may evolve and change, or alternatively, become more entrenched over time (Fordyce & Rouche, 1986; Williams, 1991). A number of factors may shape perception of injury. These factors may be loosely categorized as survivor factors, family factors, and professional factors. Survivor factors appear to include: nature and magnitude of post-injury changes in functional abilities, and co - operation in prescribed rehabilitation activities (Cavallo et. al. 1992). Family factors appear to include: family resources and coping style (Zarski et. al. 1988), expectations for recovery (Lezak, 1986), and experience with medical and rehabilitation professionals (Rosenthal & Young, 1988; Williams, 1991). Professional factors appear to include: level of awareness of the impact of the injury, communication skills, sensitivity to concerns of the survivor and family (Cope & Wolfson, 1994; Hart, Hayden & McDowell, 1989), and the ability to enter into the survivors' subjective experience of TBI (Prigatano, 1995). In combination, these factors result in congruence or discrepancy in perception of injury between survivors, families, and professionals. It has been suggested that discrepant perception of injury is one of the single greatest predictors of rehabilitation success (Schmidt, 1993). That is, as discrepancies between survivor perception of injury and other's

(family, professional) perception of injury increases, the potential for a successful rehabilitation outcome decreases.

There is frequently a discrepancy between survivor perception of injury, family perception of injury, and professional perception of injury (Condeluci, Ferris & Bogdan, 1992; Fordyce & Roueche, 1986; Hendryx, 1989). Clinical and research literature acknowledges the potential significance of differences in perception of injury in determining the course and outcome of rehabilitation with TBI survivors and their families (Fordyce & Roueche, 1986; Hendryx, 1989; Kay & Cavallo, 1992; Lezak, 1986). However, relatively few researchers or clinicians have tackled the issue of discrepant perception of injury directly. Those who have addressed this issue suggest a bias in rehabilitation treatment programs toward devaluing survivor and family perception of injury and utilizing the professional perception of injury to establish rehabilitation goals and assess outcomes (Condeluci et. al., 1992; Fordyce & Roueche, 1986). It is not uncommon, particularly in the acute care setting, for the expression of opinion by a health care professional to be construed by the family as a statement of fact (Cope & Wolfson, 1994). Particular significance is ascribed to the treating physician who is "perceived by the family as the person with the highest authority and expertise" (Cope & Wolfson, 1994, p.76). That professional opinion is based only in part on expert knowledge of empirical data and in part on the professionals' perception of this particular injury (its' impact on the survivor and the family), does not appear to be routinely discussed. Cope and Wolfson (1994) suggest that families be told from the outset "that TBI entails a lot of not knowing . . . and that staff cannot reliably or accurately provide a total patient prognosis" (1994, p. 77). Regardless of the fallibility of professional perceptions, the literature tends to view discrepancies between survivor

or family perception of injury and professional perception of injury as indicative of denial or dysfunction on the part of the TBI survivor or the family. With few exceptions (Lezak, 1986; Maitz & Sachs, 1995), the legitimacy or objectivity of the professional perception is not at issue.

Prigatano (1995) suggests that an appropriate goal of neuropsychologically oriented rehabilitation "is to help individuals attain a greater appreciation or awareness of how they have been affected (by TBI) and to help them face those problems in a manner that re-establishes a sense of meaning in their life" (1995, p.91). He states that the best way to enhance survivor awareness and to facilitate the reestablishment of meaning, is to engage the survivor in the rehabilitation process by entering his/her phenomenological field and having a sense of what it is like for him/her to have experienced a TBI.

Rationale for the Study

Research to date has focussed on attempting to quantify both the discrepancies which exist in perception of injury and the implications these may have for rehabilitation progress and outcome. This research indicates the potential interplay between, and impact of, a number of individual and subjective factors, which may or may not be present in a given instance of TBI. A greater understanding of how these factors are experienced and expressed may be gained from exploratory, descriptive research which examines the subjective experience of TBI as it is lived by the individuals who are central to the rehabilitation process: namely, the survivor, family, and treatment professionals. This type of research seems essential if we are to gain insight into how it is that survivors, family members and professionals perceive and make sense of the experience of TBI. Only by engaging in this type of qualitative research can we, as one researcher recommends, "enter (the survivor's) phenomenological field and have a sense of what it is like

for him/her to have experienced a TBI" (Prigatano, 1995, p.91). In my opinion, the lived experience and meaningful construction of TBI by each of the aforementioned parties, forms the basis for responding to it. Expanding our knowledge of the lived experience of TBI can inform and enrich both research and clinical practise in the field of TBI rehabilitation.

Given the pervasiveness and magnitude of the problems resulting from TBI, we as counsellors can expect to encounter clients who are dealing either directly or indirectly with this issue. Counsellors can, in my opinion and experience, play a central role in the rehabilitation of TBI survivors and their families. Frequently, once the initial crisis of the accident which caused the injury is past, it is the counsellor who works with the TBI survivor and/or the family to facilitate optimal adjustment to changes resulting from the injury. Learning more about the experience of TBI as it is lived and understood by survivors, family members and treatment professionals can provide us with a depth and richness of information which is currently lacking in the literature. It is this type of information which will, in my opinion, prepare us to experience, accept, and work authentically with the tragedy that has touched the lives of these clients. In doing this, we as counsellors "may bring a depth, maturity and presence to the rehabilitation process that transcends clinical experience" (Banja, 1990, p.114).

The purpose of the qualitative study reported in this thesis is twofold: to explore and describe the lived experience of perceiving and meaningfully constructing the experience of TBI from three perspectives; that of the survivor, significant family members, and the treatment professional responsible for overseeing rehabilitation services; and to gain insight into how perceptions of TBI are formed by the aforementioned persons. The question being asked is:

"How is traumatic brain injury perceived and meaningfully constructed by the survivor,

his/her family member (s), and the treatment professional responsible for overseeing his/her rehabilitation services?"

Definition of Concepts and Terms

The term TBI survivor will be respectfully used in this paper because of its prevalence throughout the brain injury literature. Lew (1990) uses this descriptor somewhat reluctantly due to the lack of a satisfactory alternative, and emphasizes 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). Given that this study will focus on individuals involved in the relatively early stages of the recovery process, the use of this term seems appropriate.

For the purposes of this study, the term family member refers to the person or persons the survivor identifies as providing significant practical and emotional support and who are accorded familial or equivalent status by treatment professionals. In some literature on brain injury, the term significant other is used and when referring to these sources, I will use this term.

The term treatment professional will be used to describe any health care professional involved in the rehabilitation process with the TBI survivor and his/her family. When referring to professional involvement in the rehabilitation process, the literature frequently neglects to specify the capacity in which the professional acts or their job title, hence this umbrella term. The proposed study will focus on the perspective of the treatment professional responsible for overseeing rehabilitation services, i.e., and the clinical case manager. An occupational therapist, psychologist, or nurse clinician most frequently plays this role.

The term perception of injury refers to "the perspectives the TBI survivor, family members and treatment professionals bring to the rehabilitation process" (Fordyce & Roueche,

1986 p.218). These perspectives are related to individual assessment of the issues or impairments which are problematic for the TBI survivor and therefore require rehabilitation intervention.

Since the perceptions of various individuals involved in the rehabilitation process will be examined, each perception will be identified as the survivor perception, the family perception, or the professional perception of injury.

The term discrepant perception of injury "refers to differing perspectives following brain injury (which) appear to have consequences for rehabilitation" (Fordyce & Roueche, 1986, p. 218). These discrepancies most frequently pertain to the nature, magnitude, or relative importance of issues or impairments which are experienced by the TBI survivor.

CHAPTER II

Review of the Literature

In order to establish a meaningful context in which to understand the phenomenon of discrepant perception of injury, in the following Chapter, I will examine selected research in the field of rehabilitation and traumatic brain injury. Topics which will be addressed include the course of recovery from TBI, family response to TBI, patterns of acceptance and denial, the impact professionals have on the survivor and family perceptions of injury, and comparisons between various perceptions of injury. Particular attention is paid to the lack of emphasis in this literature on the lived experience of perceiving and responding to the injury by any of the parties involved.

Recovery From TBI

Most spontaneous or organic recovery from TBI is thought to occur during the first six to twelve months following the injury (Smith & Godfrey, 1995). Further recovery occurs, often at a more modest pace, after this time. This later, or ongoing recovery is attributed to the individual and his/her family, learning ways to cope with changes resulting from the injury, rather than any further physical repair to the brain (Smith & Godfrey, 1995; Ylvisaker & Gobble, 1987). The length of the recovery period and the degree of recovery attained by the individual vary. This process appears to be influenced by a number of factors, including age at time of injury, severity of injury, pre-morbid personality characteristics, confidence in one's ability to recover, willingness to learn new ways to do things, and family support.

Changes in personality and mood which frequently result from TBI are most commonly reported one year after the injury has occurred (Smith & Godfrey, 1995). Prior to this time, the survivor and his/her family may be so focused on the physical repercussions of, and recovery from, TBI that they fail to notice personality and mood changes. "Family members may tend to respond not to the person in front of them, but to the person they remember. It may take months of friction and frustration for the family's pre-traumatic perception of the patient to give way to a new, more realistic view "(Lezak, 1986; p.234). A decrease in the frequency and intensity of personality and mood changes may occur by the second anniversary of the injury; however, some changes may persist beyond this time.

Most of the improvement in cognitive function occurs in the twelve months following the injury, with ongoing more gradual improvement after that time (Smith & Godfrey, 1995). Like changes in personality and mood, changes in cognitive function are most frequently reported at one year post-injury.

Recovery from TBI appears to be influenced by a number of factors, some of which are directly related to the injury, and some of which are related to survivor and family characteristics. The first anniversary of the injury seems to be a significant milestone in the recovery process. It seems that at the one year mark both the survivor and the family have had the opportunity to live with the injury long enough to begin to appreciate the impact it has had on cognition, mood, and personality. In addition, it seems likely that at this juncture, survivors and family members may be becoming aware of the potential permanence of deficits resulting from the injury.

Family Response to TBI

In the literature on family response to TBI are to be found the first examinations of inter-relationships between family adjustment to TBI and the level of recovery attained by the survivor (Livingston, 1987; Livingston & Brooks, 1988). This literature represents a departure from the line of inquiry pursued in earlier research, primarily concerned with the nature of TBI and its repercussions, which tended to use family members as "windows onto the changes and deficits in persons with head injury" (Kay & Cavallo, 1991, p.123.)

In a 1987 study, Livingston used standardized instruments to assess a total of 98 TBI survivors, together with their relatives, to gain insight into the impact of TBI on a close family member. The survivors and their relatives were divided into two groups, minor and severe, based on the medically assessed severity of injury. All survivors and their family members were seen at home three months after the injury; the severe group received follow-up visits at six and twelve months. Severity of injury, level of dependence (for the survivor), psychological symptoms, and social role adjustment (for family members) were formally assessed on each occasion. Livingston was primarily interested in determining the nature of the relatives' symptom profile following severe TBI, factors within the relatives themselves which determined psychosocial adjustment following TBI, and survivor factors impacting relatives' psychosocial adjustment following TBI. Livingston found that there were trends toward somatic complaints, anxiety and insomnia, impaired coping ability, and severe depression in both groups of relatives studied. He identified a statistically significant difference in the scores on the Leeds Scale, reflecting anxiety reported by the severe group as compared to anxiety reported by the minor group. This indicated that relatives of severely injured TBI survivors experienced significantly higher levels of anxiety

at three months post-injury than did the relatives of minor TBI survivors. There were no significant between-group differences in any of the other indicators of psychosocial adjustment.

Based on these findings, Livingston (1987) conceptualized the impact of brain injury as the burden experienced by the family in response to TBI. He made, what was at the time, a radical proposal "that a relatives' perception of the injury and objective signs of that injury may not be simply related" (p. 37). Livingston noted that inadequate or poorly communicated information from treatment professionals appeared to contribute to the relatives' inaccurate perception of injury and frequently unrealistic expectations for recovery.

There have been a number of studies done examining the burden experienced by families of TBI survivors (Livingston, 1987; Livingston & Brooks, 1988). These studies indicate that relatives of TBI survivors do demonstrate and describe the experience of emotional burden as a result of caring for their loved one. The burden does not appear to be directly related to objective signs of the injury, and in many instances, seems more related to family rather than survivor variables. In a comprehensive review of the literature on this topic, Livingston and Brooks (1988) identify a number of methodological issues which they contend compromise the generalizability, validity, and reliability of studies in this area. These methodological issues include basis for sample selection, choice of control group, relative population, as well as definition and measurement of burden. It is interesting to note that many of the issues raised relate to the role played by perception of injury. For example, the cause of the injury (i.e. assault during peacetime versus a wound sustained during active military service) is seen as an important determinant of family response. This is not due to any differences in the wound itself, but rather to the extent which the relatives may perceive that the TBI survivor is to blame for the

injury. Problems noted with the definition of burden arise from the extent to which it is a subjective one, dependent on the perception of the individual caregiver. Further difficulties are noted with a blurring of the distinction between measurement of subjective burden (relatives' complaints) and objective burden (measurable effect of burden on the relative). This is attributed to the fact that attempts to assess objective burden in fact measure relatives' perception of burden. The reviewers concluded that the practise of focusing on one relative when assessing family burden may present a picture which is incomplete and potentially misleading. They recommended further studies of the impact of TBI on the family system.

One study which looks at the impact of TBI on the family system examines post-morbid functioning in 45 family members of TBI survivors involved in post-acute in-patient rehabilitation programs (Zarski, DePompei & Zook, 1988). Family members used four different forms of self-report to provide information on family adjustment, functioning and satisfaction following TBI; the survivors were not asked to provide any information. The researchers noted some limitations of the study, including the use of self-report as the sole source of data regarding family functioning (i.e. observational data was not included), and the failure to consider TBI survivors at different stages in the recovery process, as well as "individual differences related to personality or stressors" (p. 40). The researchers concluded that the role of family functioning must be considered an important one in the rehabilitation process. They suggested that the tendency to view the family's difficulties as a direct result of the injured member is "limited and potentially harmful to the recovery process", and that clinicians can facilitate healthy and flexible coping, "by perceiving problems in circular causal loops. . . understanding the family's collective behaviour in relationship terms" (p. 40).

In their 1992 study, Cavallo, Kay and Ezrachi attempted to characterize subgroups of families based on differing perceptions of problems and changes following TBI. Thirty-four persons with a head injury (PHI) and a friend or relative of each (SO's) were asked to complete the standardized Problem Checklist. This checklist consists of 34 items dealing with physical, cognitive, behavioral and emotional problems considered common after TBI persons with a head injury were asked to rate how much of a problem each item presented for them on a scale of 1-7. Significant others were asked to independently rate the same items in terms of how much of a problem they presented for the survivor, whether or not this was a change from before the injury, and how much burden they personally experienced as a result of this problem.

The researchers found that, based on agreement between survivors and significant others on the Problem Checklist, 31 out of 34 families could be categorized into one of three groups (Cavallo et. al. 1991). High agreement families (HAF) were defined as agreeing on at least 75% of the items. High disagreement families (HD-PHI) were those with the survivor endorsing at least twice as often as the significant other on disagreement items. High disagreement families (HD-SO) were those with the significant other endorsing at least twice as often as the survivor on disagreement items. The three families that did not fit any of these patterns were dropped from the study. The researchers found that when survivors are endorsing more items as problematic than their significant others, they more frequently report executive functioning problems and affective/behavioural issues that may be subjective correlates of these items (i.e., lack of initiation). When significant others are endorsing more items as problematic than the survivor is, the items appear to be more behavioural in nature and potentially more disruptive to family life. The highest level of subjective burden was reported by the High agreement families (HAF)

group, suggesting that subjective burden is not directly or simply related to discrepancies in perceptions of problems and changes following TBI per se. In this instance, the researchers attributed the high agreement to the severity and obviousness of the residual deficits experienced by this group of survivors. Researchers tentatively attributed the high burden reported by family members to greater residual deficits or problem behaviours in this group.

Cavallo and colleagues (1991) concluded that family response to TBI is neither uniform nor random. Their results indicated that the highest burden scores resulted from the same types of items across groups, i.e., changes in personality and affect. The researchers suggested that, based on their findings, the convention of turning to families rather than to TBI survivors for more reliable information about deficits might not be appropriate.

It may be a limitation of this study that only the significant others were asked to report on the degree to which the problems identified represented a change from the survivors pre-injury functioning and the subjective burden associated with each problem identified. This precluded the collection of potentially valuable information regarding possible correlates of discrepant perception. For example, how was it that the survivors perceived and made sense of their TBI? - Did the problems they endorsed constitute a change from pre-injury functioning? What importance did survivors place on the changes they identified? Did survivors experience subjective strain/ burden as a result? It is also noteworthy that the researchers, having stated the intent to examine individual differences in family response to TBI, excluded those families whose patterns of response fell outside established response categories. The authors identify a need for further research which focuses on how individual family systems experience and cope with the deficits resulting from TBI.

Clearly, TBI has a profound effect upon the families of survivors. The way in which families experience and cope with these effects has implications for the direction and outcome of rehabilitation efforts with TBI survivors. Increasingly, clinical and research literature regarding family response to TBI (e.g. Cavallo et. al., Kay & Cavallo, 1992; Williams, 1991) acknowledges the importance of viewing families as unique, though traumatized, and providing information, support and services which are tailored to meet individual family needs. The family's perception of problems and changes (in the survivor's functional abilities) following TBI, while considered central to the progress and outcome of rehabilitation, are no longer assumed to be more accurate than those of the survivor. Families are important to the progress and outcome of rehabilitation with TBI survivors. Factors related to the family appear to influence the degree of functional recovery attained by the TBI survivor.

Sequential Patterns of Acceptance and Denial

" Family members' expectations for the patient's future can enhance or thwart their ability to cope with. . .family problems and the emotional distress created by the patient's changed behaviour" (Lezak, 1986. p.241). Some studies which examine family reaction following TBI attempt to identify individual variables related to adaptation within an interactive context (Bishop & Miller, 1988; Klonoff & Prigatano, 1988; Williams, 1991). In these studies, researchers begin to articulate the dynamic interactions among a variety of factors which influence the rehabilitation process. Klonoff and Prigatano (1988) conceptualize family reaction to TBI along two broad dimensions: functional/expected, or dysfunctional. In the former case, the family successfully negotiates the difficult process of grieving the loss of their healthy loved one and adapting to the presence of a brain injured family member. Perception is considered an

essential ingredient in a functional response. This involves "accurate self-appraisal of the limits of what the family can do and accurate appraisal of the strengths of the patient" (p. 388). In this conceptualization, denial is viewed as a natural response to the initial shock of devastating news. If denial persists over time, or results in treatment being refused, it is viewed as dysfunctional. The authors suggested that the role of treatment professionals is to "slowly and gently help families face the long term realities of brain injury. . . not with a confrontive style but by pointing out misperceptions of reality at a pace the family can tolerate" (p. 390). Other researchers have suggested that treatment professionals may inadvertently contribute to the survivor's tendency to compartmentalize their problems, thus colluding with their denial (Hart, Hayden & McDowell, 1995).

In a study which focussed on the promotion of effective interaction, intervention, and collaboration with families to facilitate successful rehabilitation of the TBI survivor, Rosenthal and Young (1988) made some fundamental recommendations regarding the role of denial in the rehabilitation process. They suggested that distinctions between potentially adaptive and potentially pathological denial be made on an individual, case by case basis. They also stressed the need for treatment professionals to recognize the potential for their impact on the adjustment process to be negative, and limit their involvement to the level at which they feel most comfortable and expert. There is some recognition in the literature that viewing denial as primarily a survivor issue is limited. "There is a need for information on the manifestations and effects of denial on patients families and on the rehabilitation staff who work with them" (Deaton, 1986, p. 238).

The presence of denial may significantly impact the perception and meaningful construction of TBI. While denial has traditionally been conceptualized as an issue for TBI survivors and their families, it is currently recognized as an issue which also affects treatment professionals.

The Impact of Treatment Professionals on Survivor and Family Perception of Injury

Williams (1991) makes a distinction between the family's reaction to the event of the TBI and the family's reaction to the survivor's resulting behaviours and characteristics, as well as the ongoing events they encounter. The family's reaction to the event of the TBI (the initial perception of injury) appears to be heavily influenced by the information they receive from treatment professionals and the way this information is delivered. Based on her clinical experience as a social worker on a neurological ward, Williams observed:

The family's perception of how professionals deliver this initial information may set the tone for future encounters. If the family is given negative information that is not born out, they may develop immediate disbelief in all subsequent information given by professionals. For those who perceive that the bad news was delivered without predictions of dire outcome, a balance of guarded optimism for the future may develop (Williams, 1991, p. 88).

Drawing on patient outcome research collected in trauma centres, managed care advocate Kenneth Hosack and brain injury advocate Carolyn Rochio (1995) wrote:

Families who receive prompt, caring and thorough assistance during this early crisis have a greater likelihood of trusting and responding to professionals in the later rehabilitation hospital and post-acute stages. . . families who receive little or no assistance, or

insensitive treatment, can develop a mistrust and suspicion of professionals that can significantly affect family participation and Cupertino" (p. 58).

Recognition of the importance of early interactions (between treatment professionals and family members) in setting the tone for the rehabilitation process has led to recommendations that professional intervention at the trauma level address the cognitive, emotional, and social needs of the family if it is to be effective (Cope & Wolfson, 1994).

Professionals enter and exit the family's life at various points in the rehabilitation process, changing the functioning of the family in subtle and not so subtle ways (Kay & Cavallo, 1991; Williams, 1991). The family must learn to deal with an often intimidating medical system which frequently uses jargon that is foreign to the lay person in order to identify and obtain the services required for the TBI survivor. Ironically, the family must rely on treatment professionals to provide them with tools to negotiate the system effectively. Prigatano (1986) notes that interpersonal exploitation at any level of the rehabilitation process has the potential to corrode the therapeutic relationship.

Maitz and Sachs (1995) drew on family systems theory in a study which examined the family's ability to adapt and cope following TBI and the survivor's success in rehabilitation. The researchers conceptualized TBI as a threat to the family structure which disrupts the balance of power among family members, creating disequilibrium within the family system. From a family systems perspective, the primary rehabilitation goal is the re-establishment of a workable family structure which includes a distribution of power and authority that meets the needs of the family and its individual members. Four case studies are presented to illustrate ways in which issues of power and authority are present and influential in the rehabilitation process. The ways in which

survivors and families feel powerless at various points in the rehabilitation process are described, along with both functional and dysfunctional attempts to re-establish a sense of power and control. The researchers pointed out that "as the family's power and knowledge increase, some conflict with the treatment team is almost inevitable"(p. 7). The issues of power and control are viewed as particularly central to the establishment of rehabilitation goals. "There is also often a lack of agreement between the family and the therapist regarding the ultimate goal of treatment. Once again, the issue centres on who has the power and authority to determine treatment goals" (p. 9).

This study emphasized the potential for power and authority issues to impact on interactions between family members and the treatment team (Maitz & Sachs, 1995). The importance of the professional recognizing and managing his or her own issues regarding power, authority, and control is stressed. The researchers concluded that family members play a major role in rehabilitation, and that the uniqueness of each family must be appreciated if interventions are to be therapeutic and effective. According to Maitz and Sachs, it is essential that professionals working with these families have a thorough understanding of the organization and operation of the family.

Families clearly play a major role in the progress and outcome of rehabilitation with the TBI survivor (Kay & Cavallo, 1991; Lezak, 1986; Maitz & Sachs, 1995). Family support has been identified as one of the determinants of survivor adjustment to the repercussions of TBI (Smith & Godfrey, 1995). The degree to which the family is able to engage and cooperate in the rehabilitation process appears to be heavily influenced by a number of factors related to the way

in which treatment professionals communicate with and respond to them (Cope & Wolfson, 1994; Hosack & Rochio; Maitz & Sachs, 1995; Williams, 1991).

Comparisons in Perceptions of TBI Consequences

The literature stresses that family perception of TBI does not exist in a vacuum. For example, in a 1986 study, Fordyce and Roueche examined the perspectives of 28 TBI survivors, their family members and treatment professionals regarding the nature and magnitude of dysfunction following TBI, before and after participation in an intensive neuropsychological rehabilitation program. Each of the participants completed the Patient Competency Rating Scale (PCRS), a thirty-item, five-point rating scale designed to measure behavioural competency in areas such as activities of daily living, emotional control, and social interaction. The researchers utilized the PCRS ratings, both as a means of systematically measuring the perspectives the TBI survivors, family members, and treatment professionals brought to the rehabilitation process, and as a measure of treatment outcome. Those survivors whose PCRS ratings most closely aligned with staff ratings were viewed as having achieved a good rehabilitation outcome. The researchers described the primary goal of the rehabilitation program as enhancing the TBI survivors' awareness of strengths and deficits and equate this with "aligning the patients' perspectives of function with those of the treating staff" (p. 218). The researchers acknowledged that "differing perspectives following brain injury appear to have consequences for rehabilitation" (Fordyce & Roueche, 1986, p.218).

Fordyce and Roueche (1986) found that discrepancies in perception included underestimation and overestimation of behavioural and psychosocial functioning by survivors as compared to treatment professionals. Family members' perceptions tended to fall into an

intermediate range initially, aligning more closely with professional perceptions following a six-month intensive rehabilitation program (as a result of an increase or decrease in family perception of the survivor's competency). Survivor perception was relatively equally divided between two categories: those who agreed with the perceptions of professionals and were receptive to treatment; and those who disagreed with the perceptions of professionals and felt they didn't need treatment. Survivors whose perceptions aligned most closely with those of the family or treatment professionals were initially more emotionally distressed than the other survivors. However, they were seen by treatment professionals to achieve better levels of adjustment following rehabilitation. The initially elevated levels of distress and the better levels of adjustment of these survivors are attributed to their lack of denial or awareness of the impact of their TBI.

Fordyce and Roueche (1986) noted some limitations of this study, including small sample size, lack of follow-up beyond active rehabilitation, and the possibility of systematic biases among professional raters. They suggest that there may be a tendency for professionals to assess more pathology in clients, particularly if the clients are resistant to treatment. The fact that the relatives' perception tended to fall between those of the survivors and professionals is viewed as an indication that "relatives' perception of injury may be augmented by their own fatigue, emotional distress, or sense of failure in rehabilitation" (p. 227). The researchers also suggest that family members may be unaware of cognitive deficits experienced by the survivor, leading to overestimation of competency.

In a descriptive study in which researchers explore the phenomenon of outcome and value of rehabilitation from the survivor perspective (Condelucci et. al. 1992), the researchers

report on the findings of three surveys (two complete and one in progress) conducted in three different locations in which questionnaires were used to elicit survivors' perceptions of a variety of factors, such as present situation, preferred situation, lifestyle patterns, and importance or value of various clinical outcomes. Survivors' perceptions were compared with perceptions of family members, treatment professionals and third parties that, in some cases, fund rehabilitation (i.e., insurance companies, and workers' compensation boards). A total of 100 survivors were surveyed and their responses were compared with those elicited from families and fee payers in previous studies. Results of this study indicate that professionals and fee payers tend to focus on functional, tangible gain, while the survivors and families appear to be more concerned with less tangible issues such as happiness, autonomy, and equality.

The literature indicates a trend toward the family perceiving emotional, behavioural, and psychosocial issues as most problematic for the survivor and therefore as high rehabilitation priorities. Survivors tend to view cognitive impairments as most problematic. There appears to be consensus regarding physical impairments (Cavallo & Kay, 1992; Condeluci et. al. 1992; Fordyce & Roueche, 1986; Hendryx, 1989). In a study examining perceptions of change following TBI, Hendryx (1989) compared the perceptions of 20 adult TBI survivors who had attained good recovery (in terms of their physical functioning, their ability to use public transit and work in a non-competitive setting) with 13 family members and 20 "healthy" controls. Each of the subjects completed a questionnaire rating 15 items related to physical, cognitive, and emotional change. Findings reinforced that families tended to rate the survivors as having undergone greater emotional change than did the survivors themselves. Survivors reported more changes in cognition than changes in emotion. Hendryx suggests that "family members may see

and react to the outward emotional frustration that the head injured family member is exhibiting and fail to perceive the changes in their injured family member that are cognitive in nature" (p. 529).

Professional perception of injury frequently evolves within the context of a multidisciplinary team. In this context, the survivor and family receive services from a number of professionals, each working within his or her own "perspectives, priorities and areas of expertise" (Hart et. al., 1995, p.143). This narrow focus may skew professional perceptions and lead to fragmentation in the development and implementation of rehabilitation goals. These problems may be aggravated if "various disciplines struggle over issues of power, status, financial support and professional recognition" (Hart et. al. p.144). Pressures within the health care system as we move toward managed care may contribute to a narrowing of perspective generally as professionals deal with limited time frames in which to provide rehabilitative intervention (Hosack & Rochio, 1995). These pressures underscore the need for Cupertino between the TBI survivor, family members and treatment professionals in the establishment of rehabilitation goals which are realistic and meaningful, given the needs and resources of the TBI survivor and the context in which he/she lives.

Having reviewed the literature, it becomes clear why facilitating recovery from TBI has been described as a complex endeavour (Fordyce & Roueche, 1986). Survivors, family members, and treatment professionals all play an important role in determining the direction, progress, and ultimately the outcome of rehabilitation. We know that each of these stakeholders brings a perspective to the rehabilitation process which may ultimately determine the outcome. However, we know very little about how these perspectives are experienced, how they interact, and how

they are expressed in the development of a meaningful rehabilitation plan. This type of knowledge seems essential if we are to appreciate the actual, subjective impact of TBI on survivors and their families, in order to facilitate optimal adjustment and recovery.

CHAPTER III

Methodology

Research Design

Relatively little is known about how a traumatic brain injury is perceived and meaningfully constructed by a survivor, family member(s), and treatment professionals. We do know that frequently there are discrepancies between survivor perception of injury, family perception of injury, and professional perception of injury, and that discrepant perceptions have implications for rehabilitation outcome. What is needed now is more in-depth information regarding the experience and meaningful construction of TBI from the perspectives of the survivor, the family member(s) and the treatment professional responsible for overseeing the case. It is through the exploration of these lived experiences that we may gain an appreciation of how the many factors which appear to shape perception of injury are experienced, expressed, and interact, leading to congruence or discrepancy in perceptions of injury.

In this research, a single case study approach was used within a phenomenological research design. A phenomenological research design is considered particularly useful when there are gaps in the literature regarding a particular phenomenon (Giorgio, 1985). The concepts and procedures of the phenomenological approach are intended to "illuminate the structure and meaning of human experience as it is lived" (Hoshmand, 1991, p.91). Since my objective in pursuing this research was twofold: namely, to elaborate the lived experience and meaningful construction of TBI from the perspectives of the survivor, family member(s) and a treatment

professional; and, to gain insight into the ways in which perception of injury are formed, a phenomenological design appeared most appropriate.

A case study is defined by interest in individual cases, not by the method of inquiry used (Stake, 1994). A case study is appropriate when the goal is to focus on a particular case specifically for the purpose of understanding its complexities. There is ongoing debate regarding what constitutes a case. Some features considered essentials if an object of study is to be considered a case include that it is "specific, unique, and a bounded system"(Stake, 1994, p. 237). According to this criterion, the experience of traumatic brain injury achieves caseness. By focusing my energy and resources on a single incident of traumatic brain injury, I elicited a greater depth and richness of information regarding the complex experience of TBI than I might using other approaches. From a purely pragmatic perspective, studying the single case was realistically within the scope of a Masters thesis. Having multiple sources of information regarding the case in the form of the perspectives of the TBI survivor, family member(s) and a treatment professional, provided both more detailed, multifaceted information about the case, and triangulation to clarify meaning.

Personal Assumptions

Phenomenological methodology recognizes that the researcher maintains preconceptions and assumptions regarding the phenomenon of interest (Osborne, 1990; Van Manen, 1990). In order to prevent these preconceptions from tainting data collection and the data itself, the researcher must make explicit her own biases, assumptions, presuppositions and theories through a process of bracketing (Osborne, 1990; Van Manen, 1990). In addition to prompting self-

awareness on the part of the researcher, bracketing alerts the reader to factors which may have influenced data collection and analysis.

Professional experience and personal interest attracted me to the topic of perceiving and meaningfully constructing the experience of traumatic brain injury. As a counsellor in private practise, I work extensively with survivors of TBI, their families, and other rehabilitation professionals. Working with survivors and their families, I have had the opportunity and the privilege to participate in the often difficult, highly personal process of rehabilitation and emotional recovery. I have witnessed the incredible courage and emotional resilience with which some individuals confront devastating loss. I have seen survivors and families pull together toward common goals and negotiate the adjustment experience, describing an increase in the cohesiveness of their family and in their satisfaction with their family life. I have also seen families torn apart by traumatic brain injury and the changes in function, role distribution and responsibility it almost always entails. I have seen treatment professionals facilitate and hinder the healing and adjustment process. I have seen treatment professionals perceived as helpful and even harmful to the adjustment process, by the survivor and the family. From my experience how well, or how completely a survivor and family member(s) adjusts to TBI seems to be heavily influenced by the ways in which they perceive and make sense of the injury and the implications it has for their lives. It appears that the ways in which they perceive the injury and the ways in which they communicate this perception to the survivor and family member(s) influence the effectiveness of a treatment professional. As a clinician, I want to be effective in my work with TBI survivors and their families. I also want to be an effective colleague and

rehabilitation team member. I believe that the type of detailed information yielded by this study will increase my effectiveness as a counsellor, and my sensitivity as a colleague.

In exploring the lived experience of perceiving and meaningfully constructing traumatic brain injury from the perspective of survivor, family member(s), and treatment professional, I assumed that the participants would describe three distinctly different experiences. I assumed that the experiences of the survivor and family member(s) would share an intensely personal tone in which the themes of loss and grief figure prominently. I assumed that the treatment professional would describe a much more clinical and impersonal approach to perceiving the injury. I assumed that the treatment professional would not initially relate to meaningfully constructing the experience of TBI, as this may seem to denote too much personal involvement with a particular injury. I assumed that the participants might not, prior to their participation in the study, have had the opportunity to reflect on and talk about their experience of TBI. I assumed that the possible link between perception of injury and direction and outcome of rehabilitation goals would have been only briefly discussed, if at all. Finally, I assumed that the participants would express a bias toward devaluing survivor and family perceptions, and describe this as destructive to the rehabilitation process.

A major expectation of this phenomenological case study was to find the meaning that each of the participants has made of TBI. I believe that the meaning making, as elaborated in this study, is most critical for the emotional health and well being of the survivor and family member(s). Having said this, I believe that the treatment professional must in some way relate with, acknowledge, and value meaning making as an integral part of adjustment to TBI, to be truly facilitative in the rehabilitation process. I expected that the personal meaning made of the

experience of TBI by each of the participants would be influenced by a variety of factors related to the injury itself, personal factors related to each of the stakeholders, and the interaction between factors. I expected that perception of injury would emerge as a central feature of the meaning-making process, and those discrepancies between survivor perception of injury, family perception of injury, and professional perception of injury would be described.

In spite of these assumptions and expectations, my overriding goal was to remain open to whatever aspects of perceiving and meaningfully constructing TBI emerged in the participants' accounts. I recognized at the outset that my assumptions and expectations might shift and change as a result of my participation in the study.

Participants

"Understanding the critical phenomena may rely on choosing the case well" (Patton & Yin, cited in Stake, 1994, p.243). In order to address the research question being asked, **"How is traumatic brain injury perceived and meaningfully constructed by the survivor, his/her family member(s), and the treatment professional responsible for overseeing his/her rehabilitation services?"** My case study design necessitated that I recruit a TBI survivor who was involved with a family member and a clinical case manager, who were also willing to participate in the study. For this reason, participants were recruited, initially by word of mouth and by letter (see Appendix A), from local rehabilitation service providers. The TBI survivor who participated in the study was 29 years old at the time of his injury. This limited the study's focus to an adult perspective, ensured the participant's independent involvement in the study, and eliminated the confounding developmental issues, which might be associated with childhood TBI. The medical classification of the survivors' TBI at the time of injury was severe, however

he had the capacity to recall, reflect upon, and report his experience of perceiving and responding to TBI.

The family member in this study was in close, regular contact with the TBI survivor. He was identified by the survivor and treatment professional as providing some practical and emotional support. At the time of recruitment he saw himself being involved in the survivor's life over the long term. The family member in this study had known the survivor for fifteen years prior to the injury. In the interests of focusing as specifically as possible on the experience and impact of TBI, survivors and family members with a documented history of psychiatric illness, or those who were actively abusing substances, were excluded.

The treatment professional that was interviewed for this study was functioning in the capacity of treating Occupational Therapist (OT) as opposed to clinical case manager. Her training and experience as an OT has equipped her with the skill to view the client in a holistic sense and maintain an awareness of the range of rehabilitation needs. The OT worked with the survivor from the time of his discharge from an inpatient rehabilitation centre at five months post injury until he had achieved functional independence at two years post injury.

The first anniversary of a traumatic brain injury seems to be a significant milestone in the recovery process. It appears that at the one year mark, both the survivor and the family are beginning to confront the ways in which the injury has affected cognition, mood, and personality (Smith & Godfrey, 1995; Ylvisaker & Gobble, 1987). I attempted to recruit a survivor who was approximately one-year post injury. I received only one response from someone who fit these criteria and he decided not to participate in the study as he was still undergoing a number of surgeries related to injuries sustained in his accident. The feedback I received from the

Occupational Therapists I was recruiting from was that they commonly received referrals of clients with TBI later in their recovery process, (ie. 12 – 18 months). They reported that clients who were at an earlier point in their recovery often did not, in the OT's opinion, have the capacity to recall, reflect upon and report their experience of TBI. I expanded the length of time elapsed since injury criterion to 30 months post injury and received no response. In consultation with my thesis supervisor, I decided to interview Curt who met all the other criteria, but was three years post injury at the time of our interview.

Recruitment

Participants for the study were recruited from the practices of local rehabilitation service providers (i.e., Occupational therapists, psychologists, speech therapists) with whom the researcher has ongoing professional contact. These colleagues of the researcher were informed of the study, by letter, (see Appendix A), and a series of follow – up phone calls, and asked to encourage individuals they perceive to be suitable for the study to call the researcher.

I screened individuals who responded in an initial telephone call to determine whether or not they meet inclusion criteria. Additional information regarding the nature of the study was provided and any questions raised by the respondent were addressed. Once I had identified a TBI survivor who met inclusion criteria I asked his permission to contact his associates (i.e. family member, treatment professional) in order to discuss their willingness to participate in the study. The first group of respondents (i.e., survivor, family member, and treatment professional) who met inclusion criteria became the participants in the study. Once participation was established, the researcher contacted each of the participants by phone to set a mutually convenient time and location for the first private and individual data collection interview.

Procedure

An in depth interview was conducted with each of the participants in the study to provide them with an opportunity to reflect upon and describe their experiences of perceiving and meaningfully constructing TBI. In order to set a tone of collaboration and ease, the purpose and nature of the study was reviewed at the outset and any questions or concerns the participants had were addressed. The participants were informed of the voluntary nature of the study and reminded that it was possible to withdraw at any time. Each participant was asked to read and sign two copies of a consent form detailing the points listed above (see Appendix B), and retained one for his/her records. The issue of confidentiality was discussed and any concerns the participants had were addressed. Each participant was then invited to choose a pseudonym which guaranteed their anonymity in any oral or written reports of the study.

The data collection phase of the interview began with a general orienting statement (see Appendix C) to maximize consistency in presenting the context of the study to participants. This phase of the interview was recorded on audiotape to allow verbatim transcription of the participants' accounts. Each participant was invited to describe his/her experience of understanding and making sense of traumatic brain injury. In order to elicit as much detail as possible in the recounting of each participant's story, minimal structure was used in the interview. Counselling skills, such as active listening and advanced empathy, were used to encourage maximal reflection on thoughts and feelings. I had some prepared questions (see Appendix D), which I referred to on a couple of occasions, to encourage further exploration of topics raised by the participants' themselves, and to stimulate further reflection by participants who seem to have "run out of steam" (Osborne, 1990, p.84). I kept process notes to detail various

aspects of the interaction, including non-verbal communication such as body language and facial expression.

The interviews continued until each participant perceived that he/she had sufficient opportunity to express his/her experience fully. This took, on average, two hours. None of the participants requested additional time. Participants were encouraged to make notes of any additional thoughts or feelings which emerged and call me to relay this information, or present it for discussion at the validation interview (described in the data analysis section).

Data Analysis

The audiotapes were transcribed verbatim by the researcher following the interview. The transcripts were read, initially in their entirety, to provide a sense of what it was the participants were describing. Since the various perspectives described by the participants appear to overlap and a number of common themes emerged, a thematic analysis loosely following that devised by Collaizi (1978) was used. In this approach, the initial reading of each transcript was followed by a second reading which focused on extracting the significant phrases which pertained directly to the experience of perceiving and meaningfully constructing TBI for each of the participants. Clusters of themes were then identified and these themes provided the foundation or focal points for the study. I chose to present these themes in a single narrative, because this seemed the most authentic and powerful way to illustrate and honour the complex context in which they emerged. In an attempt to determine the accuracy of the analysis, I conducted a validation interview with each participant. Due to time constraints, and the location of one of the participants, these interviews took place over the telephone. Prior to the validation interview each participant received a copy of the narrative containing my analysis of his or her experience. The participants

were invited to review the narrative and contact me when they felt ready to provide feedback, or talk about their responses. Both Curt and Nancy called me to talk about their responses to the narrative. Nancy reported that she agreed both with the way the information had been presented and with the themes that I had identified as salient. Nancy stated that the process of telling her story and reviewing my analysis of it had helped her put her experience with Curt into perspective, and articulate the learning she had accrued from the experience. Curt reported that he had been very moved by the account presented in the narrative. He described his initial response as agitated and upset. He stated that these feelings prompted him to talk to friends about aspects of his recovery, which were covered in the narrative. He also noted that he engaged in a process of reflection, upon both his recovery experience, and his response to the narrative. Curt ultimately stated that the narrative in fact captured and reflected his experiences, and his underlying emotions, accurately. He speculated that the “truth” of the narrative was what caused him to feel moved and agitated. Curt stated that he would continue to process his response to the narrative. Taking the time he requires to process this new information will hopefully allow Curt to integrate it into his self – structure in a way that enhances his ongoing emotional recovery. I have offered to meet with Curt to support this process, and to bring closure to his participation in this study, when he feels it would be appropriate. Feedback from the validation interviews with Curt and Nancy was taken into consideration in the final written analysis.

Limitations of the Study

The present study is an examination of the participants' experiences of perceiving and meaningfully constructing traumatic brain injury within the limits of an in-depth interview and a follow-up validation interview. These interviews are the sole source of information and as such,

are subject to several limitations. Two interviews may not be sufficient to access a complete reflection of the lived experiences of these participants. In addition issues of social desirability may have influenced the story the participants chose to tell. Since there is still some social stigma attached to being a TBI survivor, and because rehabilitation professionals may want to be viewed as competent and compassionate, these participants may have presented an overly positive view of their experiences.

A common limitation of phenomenological research and a limitation of the present study, is its lack of generalizability. Because, by definition, this approach seeks to elucidate the meaning and understanding of human experience from an individual perspective, the findings are not intended to be generalized to a larger population. However, "empathic generalizability" is achieved when the interpreted structure of a phenomenon resonates with the experience of others, not in the study, who have experienced the phenomenon (Shapiro, cited in Osborne, 1981). The goal of the present study was to explore and describe the experience of perceiving and meaningfully constructing TBI for the participants who participate. The findings, while not representative of the experience of all TBI survivors, family member(s), and treatment professionals, will be reported in sufficient detail to allow for comparison with future research and to resonate with the experiences of other TBI survivors and their family members. Recognizing that "the whole story exceeds anyone's knowing and anyone's telling" (Stake, p. 240), the researcher has attempted to provide an "exhaustive description of the investigated topic and a statement of its fundamental structure" (Colaizzi, 1978, p.61).

CHAPTER IV

The Story

Prologue

As I reviewed the transcripts of my interviews with the three people who participated in this study I was struck by the fact that many of the same issues, incidents and situations were raised in each person's account. This was contrary to what I had anticipated; namely that each person would tell a story that was more different than similar to those of the other participants. I had anticipated discovering three stories that overlapped in places, and in fact I found one story that diverges in places. Each participant's account elaborated a central story. Each participant contributed a unique perspective, which serves to amplify the themes that emerge, elaborating a central story, rich in detail and complex in character.

The story illuminates what it is like to experience, understand and make sense of traumatic brain injury from a variety of perspectives. It emphasizes the fact that while meaning making is an intensely personal process it does not occur in a vacuum. On the contrary it unfolds in a context which involves a number of people who are, or become intimately involved both with each other and with their own meaning making or recovery process. Each individual formed a perspective based on a number of personal factors in combination with their observations and experiences of the recovery and rehabilitation process of the injured individual. Each of the participants in the study described their understanding and meaningful construction of the brain injury in question as something which evolved over time.

The story, like the process that it describes, is complex and multi - faceted. The perspectives lived, and offered by the participants in the study are presented in the following chapter. These perspectives while unique, are perhaps best appreciated in the interactive context in which they were formed. I will allow the participants, as much as possible, to tell their own stories. My role as narrator is to highlight the ways in which the threads which emerge in the three perspectives weave together to form a rich and detailed narrative of the healing process. As the narrator, I too form a perspective, drawing the readers' attention to those themes and factors which appear to me to be essential to the processes of living through and making sense of the central character's brain injury for each of the participants in the study.

The story unfolds in a chronological fashion: with a beginning, the initial trauma of the accident itself and the period of acute recovery which followed; a middle, the period of approximately 9 months to 2 years post - injury where the focus was on fairly intense, community based rehabilitation; and a later portion from 2 years post - injury to the time the interviews were conducted for this study, a full three years after the injury had occurred. I believe it will become clear why there is, at this point, no end to the story. The voices you will hear are those of Curt, the survivor of a traumatic brain injury, Erik his best friend and designated family member for the purposes of this study, and Nancy the Occupational Therapist. Nancy worked extensively with Curt from the time he was discharged from the rehabilitation center at approximately 5 months post - injury until he had achieved functional independence at approximately 2 years post - injury.

The Beginning

Curt was 29 years old when he sustained a traumatic brain injury. He was working as a bush pilot at a remote fishing lodge in Northern Manitoba. He remembers this as “a beautiful, wicked time” working at a “great, great job.” Curt enjoyed the freedom the job afforded him both on the job and during the “off season” when he was free to pursue a variety of leisure activities. “I was flying seasonal. And I mean it was perfect. It was really, really fun. I had the best summers of my life.”

On the night he was injured Curt had been “partying” with friends at a local nightclub. He recalls that he became quite intoxicated and cannot remember how he got home. At approximately 2 a.m. a neighbor found Curt lying on the road outside his home. At the time what had happened was unclear. It was later discovered that he had been hit by a car and left on the side of the road with his jacket draped over his head. Curt has no memory of the accident, or the approximately three weeks following when he was in a coma. Curt has read medical reports, which describe the extent of his brain injury, and he knows that he had a Glasgow Coma Scale of 3 at the scene. This is a diagnostic rating, which reflects a severe TBI and extremely poor chances for survival. Curt laughed as he recounted this, “That’s one thing I’m kind of proud of. Cause I was the lowest they got on the scale. And yet I’m sitting here.” Curt spent approximately four weeks in an acute care hospital and a further four months in an in - patient rehabilitation center. Intensive community based rehabilitation continued for a period of 1 1/2 years, and at the time of our interview Curt remained actively involved in a process of vocational exploration geared at eventual re - entry to the job market.

Erik has been a friend of Curt’s for approximately 15 years. Curt described Erik as, “like a brother” and designated him as a family member for the purposes of this study. Erik

stated that Curt has “been there” for him through a number of his own personal crises, including a successful struggle to overcome an addiction to alcohol. Erik recalled the night of the accident as follows:

So I had dinner with them, and obviously I don't drink. They were all drinking and I decided that I would go with him to the bar and see the show. And we were at the bar for most of the night and I saw Curt and he was getting really, really drunk...for some reason, I decided to give these guys a ride back to Curt's place... I don't even know why I did that because; I wasn't going to do that. And then, probably within 10 minutes someone from out on the road sort of indicated for us to come outside and uh, there was someone lying on the road, and you couldn't even tell who it was, because of all the injuries to his face and head and everything. But, as I finally realized from what he was wearing that it was, it was Curt.

Erik's account of his own experience of the accident and the events surrounding it emphasized his sense that he did things that night he would not ordinarily have done. Erik conveyed the impression that his actions were somehow guided in a way that put him at the scene of Curt's accident, allowing him to “be there” for his friend at a very critical time. From the outset, the tone of Erik's story implied that the involvement of fate or destiny has been central to his understanding of Curt's TBI and recovery. This, for Erik, appeared to be a seminal part of his making sense of his friends' tragic accident and injury.

In a tone of voice combining horror and anxiety, Erik described the context in which his initial perception of his friend's TBI was formed:

He didn't look very good... And then he started vomiting and, I mean the biggest thing

we were trying to deal with was just making sure he kept breathing ... I was thinking that it doesn't look good at all. Like I had a really bad feeling about it.

Erik's reliance on his own intuition was another factor which emerged as central to his initial, and later perceptions of Curt's injury and recovery.

I was talking to one of the ambulance attendants and I started asking some questions and at that time he said, oh no your friend is going to be fine. And um, he certainly downplayed it, but I still didn't feel too good about it.

The initial medical prognosis was also an important factor for Erik because he believed that the medical experts would know the extent of Curt's injuries and be able to accurately predict the implications of these injuries.

We went straight to the hospital. And we sat around for around 45 minutes or so and then a doctor came in and he just came straight out and said your friend's not going to make it... if he ever comes out of this coma he won't be anybody that you know.

Erik recalled the impact of the doctor's pronouncement

I mean the fact that the doctor had just come straight out and said he's not going to make it. I mean unless he was pretty sure no one says that kind of thing to anybody.

The neurosurgeon who examined Curt at St. Paul's Hospital concurred with the emergency physician; "the top neurosurgeon came out and saw us and said the exact same thing. He said your friend's not going to make it. I guess that sort of confirmed that things weren't very good at all". The gravity of Curt's injuries and prognosis became clear and Erik had to inform the family whom, with the exception of Curt's younger brother, all live out of the country. The pain of this experience was reflected in Erik's tone as he recalled seeing Curt's younger brother

arrive at the emergency room looking to Erik for reassurance. Confronting Curt's brother seemed to force Erik to confront the seriousness of Curt's condition and its' potential implications. It was as if Curt's brother reflected to Erik the magnitude of the situation and the extent of his own helplessness in the face of it.

Erik recalled feeling devastated and overwhelmed by the seriousness of his friends' injuries and the very real possibility that Curt would not survive. He recalled felling a need to escape from the hospital and in fact from the thoughts and feelings that were going through his head. Erik recalled that this was a transitional point for him.

This is what sort of changed everything for me... I got in this elevator and I didn't know where I was going. I was just trying to find a way out... and then the thing went up to the top floor, and as the doors opened, like I just immediately had to shut my eyes ... all that I could see when that elevator opened was a round sun that just completely filled the elevator. And I just got this feeling that just came through my whole body that, I mean it was just every bit of worry was taken away by this. And I knew right there that Curt was going to be okay and it was just – I mean I can't explain it.

This experience seemed to have a profound impact on Erik and appeared integral to his own process of coping with Curt's TBI. The ethereal, transformational quality of the experience introduced an element of spirituality, which was apparent in the stories of each of the participants in the study, at various points in their recovery processes. For Erik this manifested as a sense of certainty regarding a positive outcome for Curt that sustained him during the early and ongoing recovery process. "I mean certainly I – I think throughout the whole thing I think I may have cried once. And that was in the hospital right, you know, the

day that it happened. I never thought worst case scenario here.”

Erik recalled that his outlook stood in stark contrast to those around him, Curt’s parents and the medical professionals; “everything from that point was just still negative from doctors, to family, to friends, to – it didn’t matter. Everybody that I spoke with felt there wasn’t a chance that Curt was going to make it... his dad was like, you know if he ever comes out he’ll be a mental retard. There was just absolutely no hope.” Erik recalled that the discrepancy between his outlook and that of those around him prompted him to question his own reactions. “I think I even went through a bit of a, not a crisis, but I was questioning why I was reacting to this the way I was. I almost started thinking, geez, is there something wrong with me?”

It seemed that Erik initially coped with the trauma of Curt’s injury and the possible loss of his friend as he once knew him by becoming focussed on his own internal process of responding to it. Throughout his account of the critical period of Curt’s recovery, Erik remained quite oblivious to external indicators of the gravity and potential significance of Curt’s condition. For example Erik mentioned Curt’s physical appearance, which must have been quite memorable, only in passing, “I mean it sounds kind of revolting, but his eyeball was almost hanging down to, halfway down his face.” He emphasized that he was not really affected by this at the time. This seemed to illustrate how Erik’s lack of awareness of the magnitude of Curt’s injuries prevented him from becoming overwhelmed by the gravity and potential implications of Curt’s injuries.

In a tone combining amazement and relief, Erik recalled the day Curt emerged from his coma.

Anyhow, one day, but I think I saw him the day before – one day I was at home and the

phone rings. I answer it and I say hello. And he's like oh hey Erik. I was like what are you doing? I mean he sounded completely normal... he says hi as though, you know, nothing has ever happened.

Erik described the suddenness of Curt's emergence from coma as "insane and mind boggling." At the same time he talks about it as if this type of event were to be expected, as confirmation of his belief that, "things were just going to be fine. They were going to work out." Erik's easy acceptance of this fairly dramatic event underscored the extent to which his inability to acknowledge the gravity and potential consequences of his friends' situation had been preventing him from considering a less favorable outcome for Curt.

The positive, almost casual, orientation to recovery expressed by Erik is echoed in Curt's recollections of the same time period. The matter of factness with which Curt recalled emerging from his coma set the tone, in some regards for the way in which he approached his early rehabilitation and recovery, "When I first woke up in the hospital I never questioned anything. I was just there." For Curt a central element in his initial understanding of his injury was his own sense of the normalcy of his situation.

In the beginning I didn't understand any of it. I didn't even try... and I didn't really need any help. I was normal. Like I wanted to be back to normal. But I, I guess in my mind at the same time, there was nothing wrong with me, but on another level I knew there was something wrong with me. Cause I guess I was aware there was something was wrong with me, but I didn't want to deal with it.

Here it seemed that the magnitude of what has happened to him was at the periphery of Curt's awareness. However, perhaps in order to maintain the optimism and hope he required to

recover, he could not, at that point, let it in. This sense of and striving for normalcy precluded Curt's awareness of both the extent and impact of his injuries at that time. Later in his story he, somewhat wistfully, described his understanding of how his awareness, or lack of awareness, functioned for him.

It's just in the beginning I was so I was almost like lying to myself. Like I was believing something that wasn't. Like I was pretty much ready to go, – I was fine.

Curt's sense that he was believing something that wasn't articulates the automatic, adaptive and facilitative nature of lack of awareness/ denial for the person who is experiencing it. Like Erik, Curt focussed on those aspects of his situation that were manageable at the time, maintaining optimism and motivation for a full recovery. Restricted awareness of the extent and impact of Curt's injuries and the implications these might have for the future appeared to be a powerful coping mechanism for both Erik and Curt in the early stages of Curt's recovery.

Curt seemed to cope with the trauma of his injury and potential losses associated with it by focussing on his own internal process of responding to it. This appeared similar to the way Erik coped early in Curt's recovery. The shock Curt experienced when someone responded to his physical appearance was evident as he recalled:

And uh, one woman came up to me and she said oh, you look like you've been through the wringer...that really, really affected me. That was huge. I guess I never really thought about it. I never looked at myself in the mirror.

This underscored the protective nature of Curt's lack of awareness and the very concrete ways it operated, allowing him to process the reality of his injuries at a pace he could psychologically tolerate.

At this point in Curt's recovery Erik was aware of his friend's efforts to appear normal; "Like he was always, always acting, tried acting as normal as possible. And he was just, you could tell that he was just trying to fit in" Erik, it seemed, also coped by remaining focussed on finding confirmation of his belief that full recovery, return to normalcy, would occur, "the thing that really caught my attention was that he was definitely very sharp. Like he would just respond like, I mean faster than a normal person would." It seems as that for the two men this focus was crucial to their ability to cope with the early recovery period and the associated losses for both of them.

Another factor that facilitated coping in the early trauma and recovery period for Erik and also for Curt, was the occurrence or presence of a transformational event. For Erik this was his experience in the elevator at St. Paul's Hospital. For Curt this is recalled as one of his earliest memories upon emerging from his coma.

I remember there was a man that would come and sit and watch over me and my friend saw him, but he wasn't there. And he was a white-haired man. I mean, like I definitely felt comfortable with the man sitting there. I have no answers to it really.

This man who appears to have existed only in Curt's mind, served an important role for Curt at that time, allowing him to feel safe, secure, and cared for. Curt's expression as he recalled this part of the story was excited and happy. He described his memories of the man sitting by his bed as his "favorite part of the whole story", even though he didn't recognize the man or ascribe any symbolic significance to his presence. Curt recalled how he had made sense of these events in order to integrate them, or the impact they had, into his own recovery process; "So I guess it might have been something within myself that I was projecting outside of me.

Kind of made me happy.” When relating his recollections of and reactions to this part of the story, which he included in his own, account, Erik was oblivious to the spiritual significance Curt ascribed to it. “I mean, if you would sit down with him and he’d be sitting and talking to you, but all of a sudden you’d turn around and he’d be hallucinating and he’d start talking to someone beside you and you’re just like ...And there was nobody actually there. I mean and then you’ve got to also remember, or know at that point he was on all sorts of drugs.” The fact that Erik was oblivious to the spiritual quality of Curt’s experience of the old man at his bedside underscores the fact that while spirituality was a common element for both men in their early attempts to cope with Curt’s injuries the ways in which spirituality manifested for each of them was unique, and intensely personal. Erik also seemed to need to normalize Curt’s visions of the old man at the bedside by attributing them to drug induced hallucinations.

As the early recovery period proceeded Curt gradually became aware of some of the repercussions of his injuries:

that eye is blind, my left eye. And my right eye was swollen almost shut, my knees got beat up and my head got really beat up I was like pretty much a toothpick. I was really, really thin. I remember I would get lost every single day in the hallways looking for the cafeteria.

With the exception of his reference to getting lost, Curt’s list emphasized physical repercussions of his injury. This is understandable, given that the physical symptoms were the most tangible sign that the injury had occurred, and perhaps to Curt, the most concrete and manageable focus for his attention. Erik outlined a similar list, when recalling his initial perception of the effects of Curt’s injuries. However, he placed somewhat more emphasis on

the cognitive limitations; namely short term memory loss, “I mean he still wouldn’t remember one day from the next, or even you know, 10 minutes from – he’d say the same things to me on a daily basis.” Erik was told that a common repercussion of TBI is short-term memory loss. For him acknowledging that Curt demonstrated this deficit admitted the event of the TBI and that it had had some lasting effects while seemingly containing the implications at a level he could emotionally manage.

Curt and Erik both reported that Curt was very motivated to work diligently on his recovery in the acute care and rehabilitation setting. The factors to which the two men attributed this motivation was a point where their stories diverged. Erik described Curt’s motivation as a snowball effect as he responded to the positive reinforcement he received as he progressively recovered; “I’m trying to think how the doctors were responding to that. I think they were obviously very surprised and happy with the way things were developing.” Curt attributed his motivation to a reaction against negative reinforcement he perceived from medical professionals,

I wanted to prove everybody wrong, the doctors said I’m not going to be anything. I’m going to be a vegetable for the rest of my life I guess, you’d almost think that that would slow you down, but I think that it just kind of hyped me up. I just wanted to prove them wrong so bad. That was my biggest thing in life was just to prove people – doctors wrong, I think.

Curt appeared to feel angered and challenged by the messages he perceived from the doctors. However, since his limited awareness prevented him from experiencing the impact and implications of his injury, the feedback from the doctors gave him a focus for his recovery,

while maintaining his own sense of normalcy.

During this period Curt appeared to be going through the process of integrating the reality of his injury into his self structure at an unconscious, rather than conscious level.“

I guess it's pretty obvious that uh, there was something wrong with my brain, but I don't know. I never really questioned it too much I guess, well I knew it was from the injury, but I don't remember sitting down thinking I'm brain injured, it's a really strange thing.

Curt experienced his limitations as discrete and immediate problems he had to solve, rather than symptoms of something larger, a brain injury. This appears to have helped him remain focussed on manageable tasks rather than becoming overwhelmed by the magnitude of the issue of brain injury and its' potential implications. This provided yet another example of the way in which Curt's limited and gradually expanding awareness facilitated his coping during the early recovery period.

Two closely related factors that were emphasized by both Erik and Curt as central to coping and recovery were a positive attitude and optimistic expectations. Erik reported that he had maintained a positive attitude from the time of his transformational experience in the elevator. He expected that Curt would recover fully and tended to focus on those aspects of Curt's performance/functioning that reinforced this expectation, rather than those aspects that might challenge the expectation. It seemed that for Erik a positive attitude, on his own part provided him with a sense of empowerment in coping and coming to terms with Curt's injury. Curt's positive attitude seemed to reassure Erik, that his best friend was still the same person at a fundamental level. , “He just wanted to get out and get better and he was just driven to get

better...And positive, that's just the way he is just a super positive and friendly kind of guy."

Curt described his positive orientation as central to his recovery process and, like Erik seemed to be empowered by it. "Cause uh, I guess a positive attitude is just what's kept me alive, positive thinking, just healing yourself kind of thing with a positive attitude." It is quite easy to see how these two perspectives interacted in a mutually reinforcing fashion. In a sense Erik's lack of awareness regarding the negative implications of Curt's injury reinforced Curt's sense of normalcy and anticipation of return to life, as he knew it before his injury. It seemed that the two men might have, quite unwittingly, fed off one another's optimism creating an environment where it was almost impossible to see anything other than the positive.

At approximately 5 months post - injury Curt was discharged from in -patient status at the rehabilitation center. He recalled his excitement at the prospect of moving back into the community; "I was going to move into the old house I used to live in with my girlfriend I was having then. I wanted to become an outpatient I thought that would be perfect. I could come during the day." Curt recalled with exasperation the response he received from the rehabilitation team when he reported at the discharge meeting that he felt; "good never better." The fact that there appeared to be a discrepancy between his perception of himself and the teams' perception of him seemed to be on the edge of his awareness, but was not integrated at a conscious level at that time. Curt did however continue to be motivated to prove medical professionals wrong so the existence of discrepant perceptions, even though Curt was not aware of them at a conscious level, appeared to be facilitative at that point in his recovery.

It was at this point in Curt's recovery process that the Occupational Therapist Nancy

became involved. Her initial perceptions of Curt underscored the presence and importance of his constricted awareness and his sense of his own normalcy at that time. Nancy's framing of these perceptions also provides insight into the perspective she brought to the recovery process; "He was referred to me by ICBC and he was one of my very first brain injury referrals –I've had this experience with a few clients when I first started that were not giving full effort... he had been quite the opposite...he would be really trying hard to fake his way through (assessments) in terms of how good he was." Curt's apparent "faking good" challenged any expectations Nancy might have had based on her previous experience with TBI clients. Nancy described the challenges she, as a rehabilitation professional, confronted in view of Curt's perception of his injury and abilities;

I was asked to provide a functional assessment of what his abilities were in the areas of self-care, work, and leisure. But a big problem when he was first discharged was that he was so, so acute that even his orientation was completely affected. He didn't know where he was going. It was just unreal.

Nancy recalled with humor, that Curt got lost in the three-bedroom apartment in which he was staying with his father although he insisted that he didn't have any problems. She recalled that Curt physically still appeared very injured, "So I remember seeing him and he had so much swelling in the front of his head that his eyes were like popping, he had bruises all over his face still." However, what was even more remarkable for Nancy was Curt's attitude at that time, "he was just gloating about how, how amazingly he was doing." Curt's parents decided to take him to their home abroad at that point so Nancy recalls that formal rehabilitation was put on hold. "So I gathered up as much information as I could and the next morning I met with them again to

go over as much as I could. I talked with his father about really, really making sure that no matter what, he got Curt to use the Daytimer everyday and write down everything he did. And they did do that while they were gone.” Nancy recalled that while Curt’s parents were very supportive throughout the process they had few expectations regarding his progress. “Along the way they were just ever so grateful no matter what happened. Because they were really glad just to have their son.”

When Curt returned from his parents’ home abroad three months later a period of intense community based rehabilitation began. It is interesting to note that Curt made few references to this period in his account. This may be because he was still quite disoriented and confused and as a result has no recall of this period. It could also be that this was not a particularly memorable time for him because due to his inability to engage in his own recovery at a conscious level. Erik’s recollections of this time were focussed on an intimate relationship Curt was having at the time and the impact he felt this had on his other friendships and his recovery.

Definitely from day one she was sort of at the centre of things. I guess she almost she sort of split- there was a divider that came right down in the middle because of, because of her I guess. And, uh, none of his old friends cared for her.

In spite of this Erik maintained that Curt’s recovery was progressing at a remarkable pace with remarkable results; “ he was 110% committed to doing anything that anybody suggested him do. I mean he was just super positive to, you know, he just, his goal was to get better.”

Nancy recalled that Curt’s outlook, and his perception of himself had not changed while he was away, “I did a full cognitive assessment with him when he came back and he was trying to cheat off an answer sheet.” Curt’s limitations, as indicated by the assessment were numerous

and significant. These included: impaired memory, planning, orientation, and impaired insight. Nancy recalled her initial decision to ignore many of the higher level cognitive and emotional issues in order to formulate a treatment approach that would be meaningful to Curt. Given the demonstrated limitations in Curt's awareness of his limitations at that time it is not surprising that the approach initially focussed on the physical.

we basically just started off with using that as the primary sort of treatment plan for him
And then Curt was really adamant about wanting to get physically in shape. So the gym ended up being a perfect avenue to get him back into a routine.

Nancy recognized the importance of building on Curt's strengths and using his priorities in developing an effective treatment plan. She attempted to engage him as an equal partner in rehabilitation from the outset.

Curt laughed as he recalled his desire and attempts to recover physically,
I really went hard. I was lifting weights like this big (he indicated a small space between thumb and forefinger). And I was doing little bench presses. And I was really trying hard.
Like I was, I was really trying to push myself to get better.

In retrospect Curt recognized that his perception of his functional abilities and his actual abilities at that time were very different. With hindsight Curt acknowledged that he was much more impaired than he realized at that time. Again Curt's limited awareness of the extent to which he was impaired as a result of his TBI allowed him to maintain a focus the issues he was experiencing as problematic on a day to day basis, rather than the broader, longer-term implications these issues might have. This appeared to be instrumental in Curt's coping with his TBI in early recovery period.

Nancy elaborated the challenges this presented for her as a rehabilitation professional, and the way she eventually incorporated these challenges into her work with Curt,

when we started working with him in the gym, what was really interesting to see was more of this him trying to fake his way through it. But it was just so evident that he was trying to look better than he was, cause he would have a lot of problems. He had significant problems with balance and coordination. And then the other thing that complicated things in the gym was his judgment. And he would want to prove that he was doing a lot better, so he'd want to lift like 200 pounds.

Nancy's previous experience with clients who had brain injuries was limited to individuals who in her perception were not performing to the best of their ability. Curt's presentation contrasted dramatically with these clients. Nancy recalled finding an article in the professional literature which helped her to make sense of Curt's response to his deficits and find effective ways to engage him in the rehabilitation process,

I'd come upon this article that basically makes reference to a model on building insight. And it sort of talks about the biggest part on the bottom is just the awareness before a person can sort of build on the feedback that you give them. And with Curt there was just no awareness. Like we didn't have the building blocks.

Nancy realized that Curt was unable to process information about his functional abilities accurately. He seemed unable to appreciate that his abilities had changed and that he was different than he had been prior to the accident. This echoes back to Curt's perception that he was "lying to himself" regarding the impact of his injury. Curt's lack of awareness seemed to serve a protective function, preventing him from becoming overwhelmed by the magnitude of the

adjustment issues facing him.

In an attempt to meet Curt “where he was at” Nancy focussed her interventions on providing immediate and concrete feed back to him regarding his functional abilities. This objective feedback provided Curt with information regarding his abilities and limitations. The goal was to prompt awareness, which she hoped would eventually lead to the development of insight. This approach was respectful of Curt’s right, need and ability to make sense of and engage with his injury. Concretely it offered him information regarding his changed functioning which he was free to process in order to formulate his own perception of his injury. (as opposed to a more confrontational approach that might have attempted to have Curt adopt a perception of his injury offered by another) Nancy recalled a meeting convened at approximately 9 months post - injury in order to provide Curt with a summary of his progress in rehabilitation as well as ongoing concerns of the rehabilitation team. She noted, “ he was unable to identify even, though we’d done a lot of cognitive exercises to build insight, even at that point, if cognitive exercises work. But he did start to agree that meeting regularly made a difference.” Nancy felt this was a pivotal point for Curt and their work together, “that was the very first time he ever agreed that there were problems.” Curt recalled that his awareness of his difficulties emerged gradually. “I just started realizing that oh, I guess I can’t do this anymore.”

The Middle

This shift in Curt’s awareness coincides with the transition into the middle phase of the story. This was a period of ongoing, fairly intense community based rehabilitation for Curt, which provided him with opportunities to confront his abilities and limitations in a variety of real life settings. It seemed that Curt was able to engage more fully and effectively in the

rehabilitation process because he had gone through a process of gaining awareness and acknowledging his difficulties. Both Erik and Nancy noted the importance of supporting Curt and his emerging insight and independence at this time through the maintenance, or in Nancy's case the development of a respectful and trusting relationship. Erik described how this manifested for him, "I think throughout his recovery I sort of let him go through certain things I would just sort of let Curt, sort of work with things himself." Nancy recalled that her personal rehabilitation philosophy prompted her to advocate for Curt with a feepayer when it came to the issue of gym membership. "In the end I wrote a written recommendation out and they agreed to pay for it. So, in some ways that sort of really helped build rapport with him." The trust that was developed or deepened in this phase of Curt's recovery appeared central to the events that unfolded later. Curt recalled that Nancy had been very close to him for a time and that she encouraged and supported him as he attempted to understand and come to terms with his injury.

A focal point of each of the accounts of this phase of the story is the intimate relationship Curt was involved in at the time. Each of the participants in the study described the ways in which they felt the relationship facilitated and hindered Curt's rehabilitation and recovery. For Erik, Curt, and Nancy, the intimate relationship, the way it unfolded and eventually resolved, was central to their understanding and making sense of Curt's injury and its' implications. Curt recalled the way the relationship had started,

we weren't really going anywhere with our relationship and then I was really pissed off at her just that day when I got hit. So she took the blame for the accident kind of thing and she came – and we kind of started going out when I got hit by the car.

Erik also wondered at the circumstances that gave rise to the relationship. "I don't know where

that would have ended up developing if Curt hadn't had his accident." He recalled that Curt's relationship with his girlfriend became a source of concern for him and others in Curt's support network, "none of his old friends cared for her at all and they were very concerned with what sort of an influence she would have on she would have on Curt." Nancy recalled the quality of Curt's relationship with his girlfriend, "Curt used to idolize her. And get to be with her all day. And he had quite an attachment and quite a dependence on her at that time." Nancy recalled that much of the structure in Curt's life at that time resulted from his involvement in the relationship, "And in many ways, going to the bakery and getting to the bakery on time revolved around the fact that he would get to work with her. And get to be with her all day." It seemed that initially the relationship served an important motivational role in Curt's recovery. Nancy recalled trying to enlist the girlfriend's cooperation in the rehabilitation process, "she didn't want to get involved with him as far as any education around the brain injury and had quite a strong reaction to it herself."

Curt described his girlfriend's attitude and the ways in which it affected him:

she couldn't – refused to let me blame anything on the injury. It almost got mean – I was working with her, just to get me back to normal. I would say I'm tired, I gotta sit down.

She says you're always tired – get to work. I didn't really think that much of it till later.

It didn't occur to Curt that his girlfriend's attitude was remarkably similar to his own. Even in retrospect Curt failed to see how both he and his girlfriend coped by minimizing or denying the extent of the injury and losses associated with the injury. Not surprisingly Curt initially saw the positive impact of his girlfriend's approach, "it forced me to be productive. It forced me to, to try my hardest." Curt appeared to frame his girlfriend's approach, and many other aspects of his

injury as a challenge to be met. Over time however, Curt gained insight into changes in his abilities:

There wasn't really one point I guess. Cause then I'd remember it, but it just started -
I just started thinking about my injury and my difficulties. I just started realizing that oh, I guess I can't do this anymore.

With this realization Curt's perception of his girlfriend's attitude and approach also changed;
"And I was like oh God, what a * * * "

Nancy recalled the tension that built and eventually led to the demise of the relationship;
"as things progressed and as Curt started to get better, there was constant sort of blaming and a lot of the conflict came out in the relationship, a lot of blame on Curt." It seemed that while Curt was able to acknowledge and begin to integrate the effects of his injury at a conscious level, his girlfriend wasn't. Erik too noted that a change in Curt's level of awareness led to the demise of the relationship:

She forced him into, I don't know what you would call it, but you know, she was, she was probably a pretty tough one to figure out. And I think finally after a year and a half Curt finally realized ...like I think I'm the one that's probably more normal than her.
And finally it got to the point that he realized that she had finally, outlived her usefulness, he realized that it was probably more of a detriment for him to be around her."

It seemed that in the earlier stages of Curt's recovery, when his awareness of the extent and potential implications of his injuries was very limited, his relationship with his girlfriend served a motivational and facilitative purpose. However as his awareness expanded and he began to engage at a conscious level with what had happened to him he could no longer tolerate any one

or anything that diminished or denied his experience.

Curt recalled “hitting bottom” emotionally when he broke up with his girlfriend. This is perhaps not surprising given the fact that he was beginning to process the magnitude of the losses associated with his injury at a conscious level. Nancy recalled that a number of events occurred at this time, which must have been difficult for Curt. In addition to the breakup of his relationship he had seen a neuro – ophthalmologist and been told that his vision had recovered as much as it was going to. He had been left with approximately 25% of normal vision and would never drive, or pilot a plane again. She described the impact this had on his functioning:

it was interesting because a lot of the difficulties that he had had at the start almost came back. He couldn't prioritize what he wanted to do.

Curt described a growing awareness of his increasing need to understand his injury, “when my girlfriend and I were breaking up. And I was looking for things to, for excuses, for reasons why things were – cause I was pretty down then.” Curt did not mention his consultation with the neuro – ophthalmologist and attributed his depressive mood solely to the break – up. In the later portion of the story it becomes clear that Curt did not integrate the information regarding his vision at that time. In fact at the time of our interview he stated the belief that he would drive someday.

The rehabilitation professionals Curt was working with supported him in his desire to learn about and understand his injury. Curt recalled that his psychologist encouraged him to gather information about TBI in general and his own injury in particular. His OT encouraged him to request and review copies of medical and psychological assessments he had undergone in order to empower him in his healing process. Curt had recently purchased a computer and discovered a great

deal of information on the Internet. His face lit up as he recalled his sense of relief and validation as he discovered that the difficulties he was experiencing were a result of his TBI as opposed to personal limitations;

I found a lot of cases reminded me of my own and it was really neat to read. Like somebody with the same type of injury having the same kind of problems and – I guess like associating with my injuries. Thinking that, yeah, it's because of my injuries.

This was significant in Curt's process of understanding and making sense of his injury in that it indicated a move toward linking his subjective experience with feedback he was receiving from the external world. It also clarified for him that it wasn't his deficiency as a human being, but rather the outcome of his injuries that resulted in his continued limitation. Resentment and frustration were evident in Curt's tone as he recalled what his girlfriend's denial of his difficulties had felt like for him:

I couldn't blame anything on the injury, so that's why I guess why I didn't really explore it any further cause that's. It was uh, yeah, but I guess that had a lot to do with it, too, the break up. I wanted to find out more about why I had all these difficulties. Cause they were not allowed to be, like they were never brought out cause I don't know.

At this point it seemed that Curt experienced a sense of loss and anger as he realized that he had been denying parts of himself and his own experience. His girlfriend may have provided a focus for the anger, possibly preventing Curt from turning it inward.

In contrast to Nancy's support of information gathering as a way to empower Curt in his recovery, Erik recalled feeling concerned about the potentially negative effects of Curt receiving too much information.

That was actually something that I found, disturbing, but at one point in Curt's recovery - I mean he still you know, definitely was not as far as I'm concerned at a, a point in his recovery where he should have been given a whole pile of information about himself.

Erik's concern seemed to emerge from his own lack of readiness to fully acknowledge the implications of Curt's injury and a strong sense that receiving information about the extent and implications of his injury could hurt Curt. In addition Erik appeared anxious that Curt might experience a sense of betrayal if the opinions Erik expressed to professionals, which perhaps differed from those he expressed to Curt, were revealed to him. "And you know, I was thinking, I may have said some things that I didn't want Curt to see here. You know a lot of information in there that could have really had a possibly a negative effect."

For Curt, the breakup of the relationship served as a catalyst for change and further acceptance of his injuries and limitations.

Actually the biggest change was when my girlfriend and I broke up. And then, then I just accelerated. Then I just started growing so much. I figured a lot of things out cause nobody was telling me what to do and what to think, and or anything like that. So that was a huge difference for me.

It seemed that at this point Curt was forced to experience the effects of his injury on his day to functioning. Engaging with the reality of his injuries, without his girlfriend and the structure she provided, confronted Curt with immediate and direct feedback regarding changes in his abilities and their impact on his functioning. He was then able to begin to integrate this information into his self - concept at a conscious level. "I guess that I realized that I had to be honest with myself about my injury and my difficulties if I was going to go to school." In a way this seemed like a

logical extension or internalization of the strategy used by the OT from the early stages of Curt's rehabilitation, namely using feedback to enhance insight and promote change.

Curt's way of relating to the effects of his injuries seemed to change at this time. His references to his limitations became more personal and descriptive; "my short-term memory is hugely affected. My orientation is really messed up still. Like I get lost like extremely easily. If I go into a bathroom in a mall."

The positive attitude Curt described early in his recovery and maintained throughout his recovery allowed him to view his limitations as challenges. This attitude was manifested in his enthusiastic involvement in physical, social, vocational and recreational activities designed to facilitate his recovery and enhance his quality of life. Curt's optimism prevented him from becoming panicked by his deficits or overwhelmed by the implications of his deficits. In fact, Curt seemed to be genuinely fascinated by his impairments, and viewed them as opportunities for challenging himself and learning, as the following example illustrates.

And I went to the washroom one day and, I thought oh wow, where am I. And I said, I know I'm in a bathroom, but everything out here, this room is my whole world right now. I thought it was really neat actually. Like I didn't panic or anything. I was like okay; I'm going to figure this one out.

It seemed that Curt embraced his limitations and focussed his attention and energy on learning to live with them in a creative fashion.

Nancy noted that this time marked a significant deepening in the collaborative nature of the problem identification and goal setting with and for Curt. Again Nancy attempted to use those activities that were meaningful for Curt as the focus of her rehabilitation interventions; "he

got a computer, he was quite adamant that he wanted to use that to work on problem solving and attention to detail. ” Nancy recalled that Curt purchased a fairly sophisticated, interactive computer game at the urging of one of his friends and that he was determined to master the game.

So what I did was I learned that game with him during some of our sessions. And he would tell me what he was trying to do. And I would take notes on what the skills were that he was struggling with when I would see him going through the game. I would be basically looking at him playing it and then giving him feedback on what I observed. So what we came up with was a list of the difficulties he had with that game which were; problem solving, attention to detail, note taking, memory, visual scanning and orientation. Then he was able to apply those difficulties out in the real world.

This collaborative, client centred approach to rehabilitation, seemed central to Nancy’s understanding and making sense of the ways in which Curt’s injury impacted him and the way in which his recovery could most effectively be facilitated. She noted the importance of respecting and supporting Curt’s own process and journey toward recovery. “But again with him the only way to sort of let him do it is by letting him do it and find out for himself. Cause he always needs to go try it out for himself and then he’ll come back and go oh yeah, I guess I couldn’t do it.”

This echoed an observation made by Erik regarding the importance of letting Curt “ work with things himself.” It seemed that this approach, which respected Curt’s ability to set and pursue a manageable apace for his own recovery facilitated and enhanced Curt’s recovery. Nancy respected and worked with Curt’s pace rather than trying to impose her own. Nancy in effect accompanied Curt on his journey, providing guidance and direction at points where he requested

it, capitalizing on opportunities for learning, growth and recovery as they occurred.

In terms of Erik's role he recalled that, at this time he too exploited real – life opportunities that came up, to challenge Curt, usually with positive results. For example, Erik described a camping trip he took with Curt a few months after the breakup occurred. During the week - long trip Erik noted changes in Curt's ability to work around his limitations.

At the end of that trip, he was so much better... he'd been with (his girlfriend) and I think he wasn't forced to be as independent as – I mean she really probably did a lot too much. For him to have to really work on thinking about what he was doing, where he was putting things, how he was doing it – by the end of that trip when we got back, he was very, very much more independent.

Curt's move toward independence, (literal and figurative) and self – sufficiency provided numerous opportunities for him to confront and learn to work around his limitations. Nancy recalled that Curt became involved in the renovation of the house into which he moved at that time and continued to live at the time of our interview, “ he helped finish the suite he's in now. Then helped paint it and that became the activity that motivated him after the break up. Because all his energy once he moved was devoted to making his own place.” Making a place for himself offers a metaphor for the process that was occurring in Curt's recovery at that time. As he physically engaged in the process of building a suite he was psychologically and emotionally building a new self – structure which integrated his strengths and limitations. Curt talked about the developmental nature of his adjustment and the process of becoming comfortable with his new self; “ I've really found myself through this thing, that's why I feel more comfortable cause I can let myself be myself around people a lot more. I guess it's part of

growing up, too.”

At this point in Curt’s recovery, approximately two years post – injury, Nancy discharged him from OT services, “I felt that from a functional point of view he was managing independently and he didn’t need a therapist to be involved.” Concretely Curt was living independently, he had physically regained his strength, he was using compensatory strategies consistently to work around limitations arising from his injuries, he was involved in vocational exploration and he had a good social support network. However, Nancy recalled that she realized Curt’s recovery was far from complete. “He was still struggling with psychological issues and coming to terms with a lot of things. Spiritually um, this came out with him a lot more sort of just before I discharged him.” Here Nancy was referring to the sense of loss Curt was just beginning to express regarding the fact that he would never fly again. Nancy recalled Curt saying at the time, “I don’t know. I’ve always wanted to fly. And now I’m stuck and I don’t know what I’m going to do.” The impact of the reality is amplified in Curt’s words, “But it’s uh, without flying I’ve got nothing. That’s the thing. I mean then I’m back to square one pretty much.” It seemed that for Curt the realization that he would never fly again marked the ultimate deconstruction of his pre- injury self. Not surprisingly it was also the awareness that seemed most threatening to his newly emerging sense of self. Curt recalled:

at first I really didn’t miss flying, then just recently – I was looking through my pictures and I was like oh boy, I think it’s time to start missing my flying. Sometimes I start thinking about it a little deeper. And I just catch myself kind of thing. I don’t want to go there.

The hushed, reflective and wistful tone with which Curt said this illustrated the pain of loss

associated with his increasing awareness. As he continued to rebuild his life and sense of self Curt realized that he would at times have to stifle, or shift his awareness away from certain issues to prevent himself from becoming engulfed by his emotional pain.

Nancy recognized that Curt's journey would continue and that he had developed many skills and strategies that would help him on his way.

He'd done quite a bit of writing and written quite a bit of poetry. And he shared some of that with me and I was always encouraging him to keep doing that. Because some of the things that he wrote were really interesting and they were really reflective and they helped him to look back and grow in terms of where he was at.

Curt was also seeing a psychologist for counselling regularly and had some involvement with a vocational consultant at that time. Counselling was the only supportive therapy in place at the time this study was conducted.

Later

Curt's discharge from physical, functional rehabilitation marked the transition into the later phase of the narrative of this healing process. This phase of the narrative was one where the three participants appeared to actively engage in reflection and summarization regarding what the experience has been like for them. The reflection appeared to occur due to a number of factors. These included; the time elapsed since the injury itself, the degree of physical and functional recovery achieved by Curt at this time, the shift from a focus on active rehabilitation to living a meaningful and satisfying life, and the opportunity for reflection provided by participation in the study. For Erik and Nancy this was a time when they were both, for different reasons, ready to establish some closure with the events of Curt's injury and recovery. Nancy

was in the process of discharging Curt from OT services and had to write a report summarizing her involvement with him as well as his progress toward rehabilitation goals. Erik was at a transition point in his own life having completed university. He was preparing to move on in his own life, taking up his profession and moving away from Curt geographically. For Nancy and for Erik this seemed a natural time to be engaged in a process of reflecting on their experience of Curt's injury and recovery, the impact it had had, on Curt and on them, and putting it into perspective.

Nancy described a sense at discharge that the physical and functional aspects of rehabilitation for Curt were really a small part of total picture. She felt that looking at these areas of Curt's recovery gave a false impression of how he was in fact doing. "Like I've got this tidy discharge report on function, right? But the reality is from an emotional standpoint things are just up and down with this guy all the time." Through working with Curt, Nancy gained insight into the complexity of the recovery process, and the emotional pain that is part of that process. "I think any life change will be really hard. Every time he goes through a phase in his life. Like if he has to get into a relationship again, if he ever gets married." Nancy stated that she has come to appreciate the magnitude of the impact TBI has on the lives of people who experience it, and the need for rehabilitation professionals to broaden their scope in order to appreciate this and engage in meaningful and authentic ways with survivors.

I'm starting to learn and realize more and more in working with people with brain injuries, the emotional impact continues on and on and on for much longer than we ever see it as therapists. And I think we tend to take for granted that those things are resolved

and the person is stabilized. I think it's really important to recognize that those things never go away.

Curt recalled that he realized, at around the time that Nancy discharged him, that she really didn't understand what he had been through. This seemed to surprise and disappoint him. "Then I realized that she doesn't really have a clue what it's like. She knows all the textbook stuff. But nobody knows, nobody has a clue about it really." Curt conveyed a sense of deep isolation as he talked about the inability of someone he had worked very closely with to understand his experience. This sense of isolation seems to stem from not being understood, or at a more fundamental level not being known. It is with this sense of not being known that Curt engaged in the later stage of his recovery, and may continue to struggle with in the future.

Erik's view of Curt's injury, the ways it had impacted him and the implications it had for the future seemed to reinforce Curt's sense that no one really understood the pain and loss he had experienced as a result of his injury. Erik described Curt at two to three years' post – injury as, "the same free spirited guy." Erik did not seem to be aware of, or at least did not put much emphasis on the impact Curt's injury had had on his sense of self and the incredible pain of the losses he had sustained. Erik recalled that the entire process of rehabilitation and recovery seemed to have progressed very smoothly for Curt,

it makes it hard for me to, to sort of sit back and kind of look at the way he developed and like and all that kind of stuff. 'Cause everything just seemed to keep working so smoothly that there was never any sort of periods of time where he had a real difficult time.

Perhaps Erik's sense of the ease with which Curt had negotiated his recovery was not that surprising given the fact that Curt was at times hiding his deficits and his sense of loss from

those around him. Curt recalled that he could look much more capable than he was, “I’m hiding my difficulties. That’s one thing that I’ve gotten really good at.” This tendency to hide his difficulties seems to be at odds with Curt’s sense that through his injury and recovery he had become free to be himself with people. It could also be his way of avoiding the pain of confronting the inability of his friends and family to understand the extent or impact of his difficulties.

The helplessness and frustration Curt experienced when he tried to explain the effects of his injury was reflected in the tone of the following recollection.

And uh, so it’s kind of useless to talk about it too much, about my difficulties. Cause they, they can never understand my difficulties anyway. So I can say well I get lost sometimes. I’ve told a lot of people that. I do get lost, but it just doesn’t really click in I don’t think. They just can’t understand what it’s like to have a brain injury like this. They can never understand what it’s like, to be lying in your bed thinking, about how your life was just taken away from you.

In sharing this recollection Curt’s tone and demeanor conveyed the sense of loss and despair he felt when confronted with the reality that people close to him could not appreciate the degree to which he lives with the effects of his injury daily. The discrepancy between Curt’s subjective experience and his friends’ perception of his life is underscored in the following recollection.

“Some friends have said oh yeah, I wish I had your life. I say you couldn’t handle it.” The sense that he was uniquely able to deal with the impact and implications of TBI was an important factor in Curt’s understanding and making sense of his injury and recovery. “It was good that it happened to me and nobody else in my family. Cause I think I could handle it the best. I was

fully capable of handling it. I don't know why."

Erik also implied that Curt was uniquely equipped to handle the effect and implications of his TBI. He attributed this to what he referred to as Curt's luck. Erik identified luck as a factor he considered central to his understanding and making sense of Curt's TBI. Erik commented,

he probably is an extremely lucky person in the sense that, he was able to make this recovery. I know a lot of it comes from the fact that he's very positive, but the way I see it, Curt's definitely extremely lucky.

Again for Erik the involvement of intangibles, a spiritual element was articulated. "It seems like this is a one in a million case to me. I mean I would call it a miracle." Erik also viewed his own luck as an important determinant of his response to Curt's injury.

I've had a fairly lucky life in the sense that things have usually worked quite well for me.

I've never had to deal with anything really, like the loss of a friend or the loss of a family member or anything like that. I think the worst thing that's ever happened to me is that my dog died.

In this recollection Erik failed to mention or perhaps appreciate the traumatic nature of some of his past experiences, for example his struggle with alcoholism and recovery, the near fatal injury of his best friend, a physical injury which seriously curtailed his own participation in leisure sports. This suggested that Erik tended to diminish the negative or traumatic impact of his own experiences as long as the outcome was satisfactory. This tendency seemed to be very influential in his understanding and making sense of Curt's injury.

Ultimately Erik described the effect Curt's injury and recovery had had on his friend's life as follows.

I think this accident has had a very positive affect on his life. If I look at quality of life and what's important to me, he is living a much more enriched and fulfilling life now than he ever has. I mean, he's got passion for all sorts of things. And this was through his recovery.

Erik's personal experience with life changing events and emotional recovery, while not described in our interview undoubtedly shaped his perception of Curt's situation. "I don't think he would choose to have his old life back. I think he's much happier with his life today than in the past. I don't think he would for a second choose to go back." Erik's certainty regarding the generally positive outcome of Curt's recovery and his description of some of Curt's limitations arising from his injury minimizes some of the losses Curt has sustained. "I'm sure he's thought about not being able to drive, but it's one of those things that just, he's accepted and that's fine. I mean unless it's me asking him, Curt, does it bother you that you can't fly, he's never brought it up he's just generally happy that he had the experience." Coming from a person who so clearly cares for Curt, this lack of awareness of the magnitude of his loss also reinforces Curt's perception, that no one really understands the extent and impact of his injuries. Erik acknowledged that his own perspective tended to be optimistic and that this certainly shaped his responses. "I don't know if it's just my relaxed attitude or my what happened that day in the hospital where I was just overcome by, by confidence that Curt would be okay. – I like to see the glass half full rather than half empty." Erik seemed to appreciate that his responses seemed unusual given the potential magnitude of TBI, but he attributed this to the outcome of Curt's recovery rather than his own world view. "I don't know if it's given me a very accurate, perception of what head injury is just because everything has worked out so well."

It seems that Erik's initial belief in a full recovery for Curt has functioned like a self-fulfilling prophecy. It has allowed Erik to maintain an optimistic outlook in the face of tremendous challenges. This outlook seems contingent upon Erik integrating only the positive aspects of his experiences. It appears to be central to Erik's ability to cope with adversity.

Curt does not disagree with Erik's assessment of the outcomes of his injury and recovery. His perspective does however seem to provide greater depth and richness in understanding the nature of this type of traumatic, life altering experience. Curt summarized his experience of TBI and recovery as follows,

I found it the greatest, greatest, saddest, best thing that ever happened to me. And uh, it's all those things in one. And it's huge. It's, unbelievable really it's like the craziest, weirdest, saddest, best thing that ever happened to me.

Curt's description conveyed a clear sense of the complexity of TBI and suggests that the task of understanding it and making sense of it is multi faceted and complex. He appeared wistful as he recounted how he copes with the implications of his injury on an ongoing basis. "I could see it being horrible if I thought about it a lot, if I really regretted things. But I just try to be positive about everything. And that's why it's not horrible." For Curt maintaining a focus on the positive aspects of his life and framing the repercussions of his injuries in terms of what he has retained or gained will continue be an important element in his coping. This will require some vigilance on his part as he will have to monitor his level of emotional distress as he experiences and considers the impact his injury has had and will continue to have on many facets of his life. As with his experience of missing flying Curt may have to choose "not to go there" and shift his attention and energy elsewhere.

The matter of fact tone Curt used early in his recovery is echoed as he described his ongoing adjustment, “I deal with things. You know these are the cards I’m dealt. Curt continues to look for and find the positive,

I’ve definitely got some difficulties still, and I always will probably. But, I’m just getting used to compensating and learning different ways to remember, writing things down, I never forget anything. I think my memory actually works better now than it did before the accident because I write everything down.

By choosing to focus on the positive Curt can integrate limitations he experiences as a result of his injury into a larger, generally positive self-image. For example, Curt attributed some of his emotional resilience to the organic effects of the injury. “But I heard when somebody goes through a brain injury, the way you were before can be magnified and I guess that’s one thing that was kind of magnified was my, my happiness.” Ultimately Curt focuses on what he has, rather than on what he has lost. “I’m happy with the injuries that I did get cause they could be a lot worse. I think I would rather have this – hit my head than taken my legs off, or lost all my vision, for sure.” Curt provided a simple yet elegant summary of the peace he has reached with his injury, its’ effects and the implications these have for all aspects of his life. It seems fitting that he should have the last word. “I can’t say what my life would be like if I didn’t have a brain injury, but I’m pretty happy with the way my life is right now.”

Summary

In summary, the overall tone of the story detailing the processes through which Curt, Erik and Nancy came to understand and make sense of Curt’s TBI is optimistic and at times triumphant. The complexity of dealing with and adjusting to the changes resulting from TBI is

amplified in each of the three accounts, by the juxtaposition of the significant gains Curt makes in and through his recovery, with the immense losses he sustained as a result of his injury. The processes described by Curt and Nancy articulated an expanding awareness of the ways in which Curt's life was and would continue to be affected by his injury. Through their engagement with the recovery process and with one another in that process, we see their perception of the problems arising from Curt's injury shift. For Curt this is manifested in the gradual acknowledgment of changes in his abilities and limitations as his awareness of the losses associated with his injury unfolds and evolves. For Nancy this is expressed most eloquently in her comments regarding the discrepancy between the impression of Curt's functioning conveyed by the OT discharge report, and the reality of the disruption and distress he experiences and will likely continue to experience particularly at times of life transition. Both Curt and Nancy identify the experience of loss and the pain of loss, as central to the rehabilitation and longer-term recovery process.

Erik's process, in contrast, appeared to pursue a more predetermined course following his transformational experience in the elevator. It seemed that once he felt certain of the outcome for Curt his focus was firmly directed on those aspects of Curt's function that reinforced a complete recovery and return to normal. In a sense it appeared that Erik's awareness, of the impact and potential implications of Curt's injury decreased over the course of Curt's recovery and Erik's own meaning making process. Erik seemed most aware of the magnitude of Curt's injury and potential losses associated with the injury for both his friend and himself, on the night of the accident, when confronted by Curt's brother. It was at that point, when he was perhaps feeling despairing and overwhelmed, that he sought escape on the elevator and had a transformational

experience. From that point on Erik seemed only to see or at least attribute significance to the positive aspects of Curt's recovery and post-injury functioning.

In spite of the apparent differences in the direction of changes in awareness described by Curt, Erik and Nancy, the role played by awareness in both Curt's recovery process and their own meaning making processes is emphasized in each of the three accounts. For Curt and Erik limited awareness seemed to be an essential element in coping in the early recovery period. Increased awareness was necessary for Curt to begin to acknowledge changes in his abilities arising from his injury in order to engage consciously and effectively in the rehabilitation process. In later and ongoing recovery Curt appeared to recognize the need to constrict or refocus his awareness of losses associated with his injury in order to prevent or contain emotional distress. Nancy's therapeutic involvement with Curt focussed largely on facilitating the development and maintenance of a level of awareness which would allow Curt to engage fully in his rehabilitation and recovery process without becoming emotionally overwhelmed. Her awareness of the importance of engaging Curt "where he was at" as opposed to imposing an external agenda was significant.

Both Curt and Erik emphasized the importance of a positive attitude, on both their parts, to their recovery and adjustment processes. Both men implied a sense of empowerment that appeared to flow from their attitude. It seemed that Curt and Erik were able to claim a sense of control over the impact of Curt's injury, and the associated losses for each of them, through the exercise of a positive attitude. Throughout their accounts it also seemed that Curt and Erik each felt motivated, encouraged and reassured by the others' positive attitude. The theme of personal empowerment is reinforced and elaborated in Nancy's account of her approach to problem

identification, goal setting and choosing treatment modalities with Curt.

Each of the three accounts elaborated the importance of respecting Curt's own process, as well as his ability to negotiate it. For Curt this seemed to involve confronting his limitations with a sense of adventure and creativity. For Nancy this seemed to involve maintaining a focus on Curt's needs and his goals. For Erik this seemed to involve at times putting his own reservations or concerns aside in order to "let Curt work with things himself." For Erik this seemed to be made possible by his overriding certainty that the process through which Curt achieved it would not change the outcome of full recovery significantly.

All of the factors mentioned contribute to the sense of optimism, challenge and triumph, which is presented in the stories of Curt, Erik and Nancy. Against the counterpoint of the tragedy and loss experienced by both Curt and Erik the choices they appear to have made regarding framing Curt's TBI and the impact it has had on both of them in the most positive terms is brought into sharp focus. These choices are perhaps best understood and appreciated in the broader context made possible in the three accounts by the recognition of the presence and significance of the spiritual. For Curt and for Erik embracing the spiritual aspect is essential to making sense of the event and outcome of Curt's injury and its' impact on both of them. It is perhaps this, most of all which allowed the two men to ultimately experience not destruction, but transformation.

Chapter V

Discussion

The question I explored in this study was **“How is traumatic brain injury perceived and meaningfully constructed by the survivor, his/her family member and the treatment professional responsible for overseeing his/her rehabilitation services?”** My objective in examining this question was twofold: to explore and describe the lived experience of perceiving and meaningfully constructing the experience of TBI from three perspectives; and to gain insight into how perceptions of TBI are formed differently by each of the individuals involved in this experience.

The narrative contained in the preceding chapter provides a rich and detailed account of what it was like for three individuals to understand and make sense of TBI. The ways in which the stories unfolded conveyed the sense of healing as a journey or evolution. The narrative articulated factors, which were, in this case, significant to the formation of perception of injury by the individuals involved. The ways in which the experiences and perceptions of this survivor, family member, and rehabilitation professional were similar or discrepant were elaborated as well as the ways they interacted. The interaction of these factors appeared to influence the ways, in which each individual endeavored to understand, make sense of and adjust to the injury and the implications it had for the survivor and their relationship with the survivor. The stories illuminated factors, which were central to the coping, recovery, and meaning making processes of Curt, Erik and Nancy.

In this chapter I will discuss a number of issues which emerged as central to the recovery and meaning making processes of the participants in the study. These include; the sense of recovery as a process, the role of awareness in coping with, and adjusting to TBI, the importance of spirituality, and optimism in the recovery process; and the importance of collaborative goal setting and client centred rehabilitation as it was applied in this case. I will begin by clarifying how I identified these as significant issues or themes. I will then examine ways, in which these themes complement or contrast with information contained in the professional literature, thus illustrating the ways in which this information elaborates or challenges current thinking. I will comment on the implications that information gathered in this study has for counselling practice and for further research in this area. Finally I will briefly reflect on how the experience of conducting and participating in this study has affected me, as a person, and as a counsellor.

The Identification of Significant Themes

My interviews with Curt, Erik and Nancy yielded a wealth of information about their own experiences of understanding, making sense of, and adjusting to Curt's TBI. One of the most compelling aspects of the experiences for me was the presence of respect, growth and personal empowerment in the interactions between the individuals telling their stories both with one another and with their own recovery processes. Each of the individuals articulated a sense of being personally enriched by the experience of understanding and making sense of Curt's TBI. It is this sense of personal enrichment in the face of tremendous tragedy and loss, that best characterizes the stories of these three individuals, and in particular of Curt. It is this aspect of the experiences of Curt, Erik and Nancy, and the factors that appeared to contribute, that I was

motivated to describe, illuminate and elaborate in presenting, what are for me, the salient themes in their accounts.

Recovery as a Process

Each of the participants in this study described their understanding and meaningful construction of the TBI in question as something which evolved over time. The ways in which the processes unfolded, particularly for Curt and Erik, appeared to be influenced by a number of personal factors including; awareness, psychological and emotional readiness to process information regarding the impact and potential implications of Curt's TBI, the availability of information regarding Curt's TBI, expectations for recovery, and spirituality. Nancy too described a progression in her work with Curt which, for her, appeared to coincide with an evolving sense of awareness of the nature and the importance of his own process in determining appropriate and meaningful rehabilitation interventions.

Kay and Cavallo (1992) acknowledged the evolutionary nature of recovery from and adjustment to TBI. They defined this evolution as "an ongoing process of adapting to current realities" (p.122). They also described a process of redefinition of the self, which they suggested is central to the rehabilitation and recovery of TBI survivors.

In its broadest outlines, this process involves moving from a state of relative unawareness of the new self, through the identification of self as a "head injured person" to a final stage of identifying oneself as a person – who happens to have a head injury (P.140)

This way of conceptualizing recovery from TBI and the challenges inherent in recovery seems to reflect the fluid and flexible processes described in the present study more accurately than the stage theories that had previously been proposed.

For example, Lezak (1986) had suggested a six-stage process that she thought described the experiences of families confronted with the task of adjusting to the presence of a member with TBI. These stages are seen to correspond with the families' emotional response, as they become aware of the ways in which their loved one has been affected by TBI, and as their expectations for recovery change. In this model the family initially experiences a sense of happiness at their loved ones' survival and expects a full recovery. Over the course of a two year period, feelings of happiness are seen to give way to: anxiety; depression; despair; mourning; reorganization, and ultimately disengagement from the injured family member; as the family begins to appreciate the implications of the injury and resign themselves to the fact that further recovery is unlikely. The stages and responses described by Lezak do not appear to be reflected in the current study. However, her comments that, "the stages overlap and recede and reappear in very unlinear ways ...people need to see some things for themselves" (p.244) seem to have some application to the processes described by Curt, Erik, and Nancy. Specifically it seems that while there appeared to be some commonality in the phases, or stages that Curt, Erik, and Nancy went through in their recovery processes, the timing, order and duration of the stages was different for each of them. This reinforces the importance of recognizing and honoring the uniqueness of each individual's recovery process. It is essential that stage models are viewed as a tool in understanding and supporting recovery from TBI, not as a rigid prescription for how recovery " should occur."

The Role of Awareness in Coping With and Adjusting to TBI

In the accounts presented by Curt, Erik, and Nancy, awareness of the impact and implications of the injury, emerges as a central factor in understanding, coping with, and adjusting to Curt's TBI. The fact that there were changes in awareness over time and that these

changes, particularly for Curt, appeared to coincide with increased emotional or psychological readiness and ability to acknowledge and begin to integrate the impact and implications of his injuries, underscores the gradual, process nature of adjustment to TBI. Much of the literature in the area of TBI tends to focus on denial as opposed to awareness, conveying a somewhat negative connotation of any restrictions in awareness on the part of the TBI survivor or family member (Bishop & Miller, 1988; Klonoff & Prigatano, 1988; Lezak, 1986; Williams, 1991). In this study, we see the adaptive and in fact facilitative nature of restricted awareness for both Curt and Erik. Maintaining a narrow, in Curt's case gradually expanding, awareness of the impact and potential implications of the injury allowed Curt and Erik to maintain an optimistic outlook, and to focus and build on Curt's strengths, as they emerged in the recovery process.

While there is some recognition in the literature that awareness is central to the rehabilitation and recovery process with TBI survivors and their families (Fordyce & Roueche, 1986; Prigatano, 1995), there seems to be some disagreement regarding the role awareness plays and how it is measured or assessed. Fordyce and Roueche equated enhancing the TBI survivors' awareness of strengths and deficits with "aligning the patients' perspectives of function with those of treating staff" (p.218). Prigatano suggests that supporting survivors' in developing a greater awareness of the ways that they have been subjectively affected by TBI is both an appropriate rehabilitation goal, and an effective way to engage the survivor in the rehabilitation process. Curt's experiences working with Nancy, as described in the present study, seem more consistent with this latter view.

In Curt's case, particularly in his work with Nancy, the effectiveness of working with a growing awareness in ways that are meaningful to the injured individual is illustrated. Nancy's

focus on providing Curt with opportunities to receive feedback on his performance, in real life situations which were important and meaningful to him (i.e. the gym, the computer game), supported him in gaining increased awareness at a pace he could tolerate. Klonoff and Prigatano (1988) recognized the importance of the treatment professional adhering to a pace that is manageable for the client(s) in nurturing survivor and family awareness and facilitating adjustment to TBI. They suggested however, that the role of the professional in their work with TBI survivors and their families is to, “point out misperceptions of reality ” (p.90). The approach used in the present study, namely working with the survivor’s emerging perception of reality, contrasts with these findings. The fact that Curt ultimately realized that he would, at times, have to shift his awareness away from certain repercussions of his injury and the losses associated with his injury, illustrates the dynamic, fluid, and flexible nature of awareness. It also highlights the importance of emerging awareness in coping with, and adjusting to, the long-term effects of a life altering experience like TBI.

The Importance of Spirituality and Optimism in the Recovery Process

Nowhere in the literature did I find any reference to the importance of spirituality to the recovery or adjustment process for the TBI survivor or family members. It may be that spirituality is subsumed under the heading of “individual factors” referred to in the literature as influencing both the length of the recovery period and the degree of recovery attained by TBI survivors and their families (Smith & Godfrey, 1995; Ylvisaker & Gobble, 1987; Zarski, et. al., 1988). The presence of a spiritual aspect was central to the coping and meaning making processes of both Curt and Erik and was validated, honoured and implicitly incorporated into the rehabilitation process by Nancy. It seems logical to discuss spirituality and optimism in the same

section when considering the stories of Curt and Erik because there was so clearly an interaction between these two factors, which was central to their perceptions and meaningful constructions of TBI.

While Erik described himself as an optimist by nature, a “glass half-full” kind of guy he attributed his ability to maintain optimistic expectations for Curt’s recovery in the face of Curt’s injury, to his transformational experience in the hospital on the night of the accident. Lezak (1986) emphasized the significance that family members’ expectations for recovery may have for both their own adjustment and for the survivors’ progress in rehabilitation. This relationship between expectation and outcome was certainly illustrated in the present study. Erik’s ability to place Curt’s injury in a much broader spiritual context, seemed to be central to his understanding of, coping with, and adjusting to, Curt’s TBI. Erik’s openness to the spiritual allowed him to celebrate Curt’s recovery as “a miracle” and to view his friend as a source of inspiration.

Curt also identified optimism as central to his process of understanding, coping with, and adjusting to, his TBI. His sense of the involvement of the spiritual, as manifested in: his experiences with the old man at his bedside; his belief that he had the power to heal himself; and his sense that he was uniquely equipped to deal with the effects of his injury; supported and fuelled his optimism. By viewing his injury against the broader context offered by the inclusion of the spiritual aspect, Curt was able to experience an empowering personal transformation and in fact “find himself” through the recovery process. Prigatano (1995) identified the need for TBI survivors’ to re-establish a sense of meaning in their lives in order to move beyond the trauma of their injury and achieve optimal recovery. This suggests a very powerful role for spirituality in

the recovery process and reinforces the importance of qualitative research to access this type of information.

Nancy acknowledged the influence and significance of the spiritual element as well, as she prepared to discharge Curt from OT services. Her sensitivity to, and respect for, the importance of the spiritual for her client, his losses and his recovery challenges, while not articulated in goals set with Curt undoubtedly informed and facilitated her intervention with him. Nancy's work with Curt encompassed and implicitly supported the pursuit of intangible as well as functional gain or progress. The approach to rehabilitation taken by Nancy incorporates elements identified in the literature as important to both TBI survivors and their families, and treatment professionals and feepayers, when assessing treatment value or outcome (Condeluci, et. al., 1992). Adopting a broader perspective to rehabilitation through the inclusion of the spiritual, may have significant implications for decreasing the fragmentation in the development and implementation of rehabilitation goals which has been identified as a deterrent to optimal recovery (Hart, et. al., 1995).

The Importance of Client Centred Rehabilitation

One of the most striking aspects of Nancy's story was her focus on building on Curt's strengths and utilizing his priorities in the development of a treatment plan. From the outset of her involvement with Curt, Nancy seemed determined to enter his assumptive world and meet him "where he was at". This was manifested in numerous ways including her decisions, at various points, regarding the focus and modality for treatment interventions. This approach is very consistent with that endorsed by Prigatano (1995) who suggested that the most effective way to facilitate optimal recovery with TBI survivors may be to "engage the survivor in

the rehabilitation process by entering his/ her phenomenological field and having a sense of what it is like for him/her to have experienced a TBI" (p.91). Nancy's approach to rehabilitation with Curt was respectful of his needs and his ability to engage with, make sense of, and adjust to, the effects of his injury. Rather than imposing her own agenda, Nancy was able to follow Curt's lead, allowing him to set the pace and direction for rehabilitation. This approach seemed to be both empowering and effective for Curt. He reported feeling supported and encouraged by Nancy. Maitz and Sachs (1995) generally describe the potential for issues of power and control to impact on the setting of rehabilitation goals, and the rehabilitation process. These researchers identified the importance of professionals recognizing and managing their own issues regarding power authority and control. Implicit in these findings is the importance of empowering the client. The importance of focusing on individual needs and approaching the establishment of rehabilitation goals and priorities, on an individualized, case by case basis is acknowledged by a number of researchers (Cavallo et. al, 1991; Kay & Cavallo, 1992, Klonoff & Prigatano, 1988; Zarski et. al., 1988). Having said this it is important to remember that the rehabilitation process flows out of, and has historically been shaped by, the medical model, which views the doctor as the expert. Several researchers have suggested a bias in rehabilitation toward devaluing survivor and family perception of injury and utilizing professional perception of injury to establish rehabilitation goals and assess outcomes (Condeluci et. al., 1992; Fordyce & Roueche, 1986). Further research which elaborates those factors that facilitate collaboration and cooperation between TBI survivors, their families, and rehabilitation professionals is needed.

Nancy expressed a sense of personal and professional growth and enrichment through her interactions with Curt. She reported that she gained a greater appreciation for both the

magnitude, and duration of, the emotional, psychological, and spiritual impact of TBI which she feels will make her a more informed and effective therapist. Banja (1990) suggested that clinicians who accept, and work authentically with the tragedy that has touched the lives of these (TBI) clients will be enriched through the process, and will bring a depth and presence to their work “ that transcends clinical experience”(p. 114).

Implications for Counselling Practice

Prior to embarking on any discussion of the implications information gathered in this study may have for counselling practice it is imperative to emphasize that the case of Curt, Erik and Nancy is unique. Qualitative research does not allow for generalization to a larger population except in the sense of empathic generalization (Osborne, 1990). This is where individuals who have experienced TBI, either directly (as in survivors) or indirectly (as in family or treatment professionals) upon reading the data, may resonate with it. Given the intensely personal nature of the experiences described, and the multitude of individual and interactive factors which are unique to this case and could not be recreated in other situations, it is impossible to generalize to other survivors, family members or other professionals in other circumstances. However, having said this there is information contained in the data that may inform counselling practice, making the intervention of counsellors working in this area more compassionate and effective.

One of the issues illustrated by this case which may have important implications for counselling is the sense of recovery from TBI as a gradual evolution or process. The role of awareness in this process appears to be significant. In the case of Curt and Erik constricted awareness was central to coping and maintaining optimism in the early, (and for Curt), the ongoing recovery process. Gaining awareness and being able to acknowledge the impact, and

potential implications, of his injuries was essential to Curt engaging fully and successfully in the rehabilitation process. The process through which he gained this awareness appeared to be intensely personal and a necessary part of his recovery. Lezak (1986), writing about psychological interventions with the families of TBI survivors, points out, that in order to be effective, counselling interventions must recognize and incorporate the families' readiness and ability to receive and process information about their loved ones' impairments and implications these may have for the survivor and for the family. Klonoff and Prigatano (1988) suggested that the role of the treatment professional is to "slowly and gently help families face the long term realities of brain injury" (p.390). As counsellors, we may at times be tempted to force our clients to deal with "reality" at a pace we deem appropriate due to our own discomfort with the situation we perceive them to be in, or due to discrepancies between their perception of reality and "objective reality". We as professionals, skilled in promoting healing, may be impatient for the client to "get on with it". This may prevent us from seeing, appreciating and supporting the client's own healing process as it is manifested in the pace and the focus for recovery which is set by them. Fordyce and Roueche (1986) identified a tendency for professionals to assess more pathology in clients whose perceptions of injury differ from those of treatment professionals and who may therefore be considered resistant to treatment. As counsellors it seems important that we maintain awareness of our own perception of injury versus the clients' perception of injury when working with TBI survivors, and avoid imposing our own agenda on their recovery and rehabilitation. A number of researchers have identified the potential for factors unrelated to the survivor and his/her needs and priorities to influence the setting of rehabilitation goals. These factors include: rehabilitation outcomes valued by treatment professionals and feepayers;

(Condeluci et. al., 1992); professional perception of injury (Fordyce & Roueche, 1986); competition and other tensions within the interdisciplinary rehabilitation team (Hart et al., 1995); and the treatment professionals' own issues with power, authority and control (Maitz & Sachs, 1995).

In the stories of Curt Erik and Nancy awareness of the implications of Curt's TBI shifted over time, increasing or decreasing as a function of the unique recovery processes of these individuals. The fact that Nancy, and to a lesser extent Erik, were able to respect, value and work with Curt's shifting awareness seemed to be central to Curt's recovery and the establishment and maintenance of positive, supportive, relationships between these individuals. Prigatano (1995) suggested that a willingness to enter the client's phenomenological field and to maintain a focus on the client's subjective experience and priorities could have a significant impact on the rehabilitation and recovery process. The information gathered in this study demonstrates some practical ways in which Nancy was able to enter Curt's phenomenological field. These included: attending to his rehabilitation priorities; working at his pace; providing guidance and direction at points where he requested it; and capitalizing on opportunities for learning, growth and recovery as they occurred.

A client centred approach with individuals who may experience cognitive impairments presents some special challenges. Nancy found that she had to provide Curt with opportunities to receive information regarding his performance in real life settings in order to facilitate an increase in awareness and promote the development of insight. This has some implications for counselling in that it may be necessary to incorporate strategies into counselling which will address or compensate for any cognitive limitations the client may have. Carberry and Burd

suggested that the therapist working with adult TBI survivors “ needs to work on cognitive deficits and retraining, yet still work within the context of the life problem that brought the patient into therapy” (1986, p.24). These researchers recommended the incorporation of specific strategies in the counselling setting. These included: the use of direct questioning and redirection to help the client maintain focus; the use of verbal and written summaries, and note taking on the part of the client to enhance attention and concentration; the use of brainstorming to compensate for cognitive rigidity; and a focus on empathy training to compensate for egocentrism the client may experience as a repercussion of their injury. Attending to the cognitive as well as emotional needs of the client seems essential if counselling is to be truly accessible to persons with TBI.

A holistic approach to rehabilitation and recovery was very effective and empowering in Nancy’s work with Curt. It allowed for inclusion of those aspects of Curt’s self, which, even though not directly addressed in rehabilitation goal setting, were instrumental in his recovery. It also prompted Nancy to support Curt in accessing, and focussing all the resources he could bring to bear on his recovery process (i.e. information gathering, reading, creative writing). If we, as counsellors, are to support our clients in the re-establishment of meaning (Prigatano 1995) it seems critical that we are sensitive to, and supportive of, any means available to them. Hart et. al., (1995) recognized the potential for fragmentation in the development and implementation of rehabilitation goals within the context of the multidisciplinary team. As counsellors working with TBI survivors and their families it seems essential that we maintain an awareness of, and if necessary advocate for, the clients’ rehabilitation needs and priorities. It also seems critical that we are able to work collaboratively with other members of the clients’ rehabilitation team.

In her work with Curt, Nancy realized that the somewhat narrow or short-term focus traditionally taken by rehabilitation professionals, in particular Occupational Therapists, does not recognize the ongoing emotional and psychological impact of TBI. Literature suggests that bulk of spontaneous recovery from TBI occurs during the first two years following the injury (Smith & Godfrey, 1995; Ylvisaker & Gobble, 1987). While it is implicit in the literature that further adjustment may occur after that time, the two-year mark is emphasized as significant. Lezak (1986) uses two years as a time frame in which the families of TBI survivors work through the stages of adjustment to the injury of their loved one. In Curt's case a lot of the emotional psychological and spiritual issues only began to emerge at around the two-year mark. The need to take a broader, longer-term view of adjustment to TBI has implications for both the timing and the duration of counselling interventions with TBI survivors and their families. Kay and Cavallo (1992) suggested that even when the TBI survivor has emotionally recovered, to the point where they have re-established a meaningful and satisfying identity, their emotional recovery, and indeed their need for support is ongoing. They attributed this to the cognitive deficits which may cause the survivor to "lose the mental set of this new identity quite easily" and therefore render them "dependent to some extent on others to help them hold onto the reality and rationale of the changed self" (p.141)

Implications for Future Research

The information gathered in this study provides a rich and detailed account of what it was like for three individuals to understand, cope with and adjust to Curt's TBI. Many factors were elaborated which appeared to be, in this case, central to functional coping, successful rehabilitation intervention, and adjustment to TBI. A limitation of the present study is the fact

that the findings can not be generalized beyond the individuals who participated in it. I would recommend additional research, which looks at the lived experiences of a number of TBI survivors together with their family members and treatment professionals. A larger, and more diverse sample would: facilitate the identification of additional themes which characterize these experiences; elaborate the interactions between the perceptions of the individuals sharing the experience and the implications for rehabilitation and recovery; as well as to further refine the themes presented in this study.

The present study explored the experiences of a male TBI survivor and his male family member. Both men are Caucasian and were single, young adults at the time the injury occurred. Both of these men are self-described optimists, and members of the middle class. Both men report that their lives prior to the accident were happy and relatively carefree. Further research which explores the experiences of male and female survivors and family members, at various stages of adult development, from different cultural, ethnic, and socio-economic groups, who describe a variety of life experiences leading up to the injury, as well as a less optimistic world view, will greatly enhance our awareness of the variety of individual factors which contribute to understanding and making sense of TBI.

The approach to goal setting and rehabilitation generally, taken by the treatment professional in the present study seemed to have a significant, beneficial and facilitative influence on Curt's, and by association, Erik's process of understanding and making sense of Curt's TBI. Further research which examines the impact and outcome of a variety of treatment approaches will enhance our knowledge of the elements of effective rehabilitation intervention. Given the fact that rehabilitation goal setting and implementation most commonly occurs within

the context of a multi-disciplinary team, it seems important to pursue research which will provide greater insight into the ways in which TBI is perceived and meaningfully constructed in the team context.

The present study is confined to exploring and describing the experiences of a survivor of a severe brain injury. The findings of the study suggest that the diagnostic category, combined with the significant level of physical and functional recovery achieved by Curt were important in shaping his perceptions, and the expectations and perceptions of his family member and treatment professional. Further research with survivors who have less severe injuries, as well as different levels of functional and physical recovery is needed to elaborate the relative contribution these factors make to understanding and making sense of TBI

The present study indicates that recovery from TBI is a process which may be facilitated by a variety of factors. In order to enhance our knowledge of both the ways in which the process unfolds and the factors, which may be facilitative in this unfolding, it seems important to pursue longitudinal research. By examining and documenting the experiences of a large and diverse group of TBI survivors, family members and treatment professionals, over a number of years it may be possible to more accurately and fully assess the natural course of recovery and the optimal timing of facilitative rehabilitation intervention.

Reflections on Conducting and Participating in This Study

Conducting and participating in this study has challenged some of the assumptions I held at the outset. I had thought that the participants would describe three distinctly different experiences of understanding and making sense of TBI. I had thought that the experiences of the survivor and family member would share a personal tone, as opposed to the clinical tone I had

assumed would characterize the treatment professional's story. I had thought that themes of grief and loss would be central in the stories of the TBI survivor and family member, and that I would discover a bias toward devaluing survivor and family perceptions of injury in the development of rehabilitation goals. While themes of grief and loss were implicit in the stories of Curt and Erik they provided the counterpoint to the themes of optimism, personal empowerment and transformation which seemed more central to the stories and experiences of these two men. The tone of Nancy's story as she recalled her work with Curt reflected the authentic and respectful nature of their working relationship. Not only did Nancy seem to value Curt's perception of his injury; she worked with and from this perception devising rehabilitation goals and priorities that were meaningful for Curt. I embarked on this study believing that discrepancies in perception of injury held by the survivor family member and treatment professional were inherently destructive to the rehabilitation and recovery process. In the case of Curt, Erik and Nancy I have come to appreciate that it is not the existence of discrepancies in perception that is harmful. Nancy was able to work effectively with Curt even though there was a discrepancy between her perception of his injury and his. The key to this would appear to be her ability to set aside her perception in favour of Curt's when developing rehabilitation goals, or letting her perception inform rather than direct her intervention with Curt. Similarly Erik was able to set aside his perception of what Curt needed when Curt's perception differed from his, "letting Curt work with things himself".

I was touched and humbled by the stories I heard. I was reminded of the degree to which my own biases and expectations can colour my experience. I have been enriched by this experience and believe that I bring increased awareness, sensitivity, and respect for the client to

my counselling work as a result

References

- Bennett, T.L. (1989). Individual psychotherapy and minor head injury. Cognitive Rehabilitation 7 (5) (pp. 20-25).
- Bennett, T.L. (1987). Neuropsychological counselling of the adult with minor head injury. Cognitive Rehabilitation, 5 (1), 10 -15.
- Bishop, D.A., & Miller, I.W.(1988). Traumatic brain injury: Empirical family assessment techniques. Journal of Head Trauma Rehabilitation, 3 (4), 16 - 30.
- Carberry, H., & Burd, B.(1986).Individual Psychotherapy with the brain injured adult. Cognitive Rehabilitation, 4 (4), 22 – 26.
- Cavallo, M.A., Kay, T., & Ezrachi, O. (1992). Problems and changes after traumatic brain injury: Differing perceptions within and between families. Brain Injury, 6 (4), 327- 335.
- Condeluci, A., Ferris, L.L., & Bogdan, A. (1992). Outcome and value: The survivor perspective. Journal of Head Trauma Rehabilitation 7, (4), 37 - 45.
- Cope, D.N. & Wolfson, B. (1994). Crisis intervention with the family in a trauma setting. Journal of Head Trauma Rehabilitation, 9, (1), 67 - 81.
- Deaton, A.A. (1986). Denial in the aftermath of traumatic head injury: Its manifestations, measurement and treatment. Rehabilitation Psychology, 31, (4), 231 - 238.
- Fordyce, D. J., & Roueche, J. R. (1986). Changes in perspectives of disability among patients, staff and relatives during rehabilitation of brain injury. Rehabilitation Psychology, 31, (4), 217 - 228.
- Giorgi, A. (1975). An application of phenomenological method in psychology. In A. Giorgi, C. Fischer & E. Murray (Eds.), Duquesne Studies in Phenomenological Psychology, Vol. 2, (pp. 82-103). Pittsburgh: Duquesne University Press.
- Griffith, E.R. (1990). Types of disability. In M. Rosenthal, E.R. Griffith, & M.R. Bond & J.D. Miller (Eds.) Rehabilitation of the head injured adult. (Pp.37 –48) 2nd ed. Philadelphia: F.A. Davis Co.
- Hart, T., Hayden, M.A., & McDowell, J. (1989). Rehabilitation of severe brain injury: When you stick to the facts you cut the losses. In J.E. McGrath (Ed.), Neurotrauma (pp. 170 179). New York: Holt, Rhinehart & Whitstone.

Hendryx, P.M. (1989). Psychosocial changes perceived by adults and their families. Archives of Physical Medicine and Rehabilitation, 70, 526 - 530.

Hosack, F. R., & Rochio, C.A. (1995). Serving families of persons with severe brain injury in an era of managed care. Journal of Head Trauma Rehabilitation, 10, (2), 57 - 65.

Hoshmand, L.L.T. (1994). Orientation to inquiry in a reflective professional psychology Albany, New York: State University of New York.

Kay, T., & Cavallo, M.M. (1991). In J.M. Williams & T. Kay (Eds.). Head injury, a family matter (pp. 121-147). Maryland: Paul H. Brooks.

Klonoff, P., & Prigatano, G. (1988). Reactions of family members and clinical intervention after traumatic brain injury. In M. Ylvisaker & M. Gobble (Eds.) Community re-entry for head injured adults. (Pp. 381 - 402). Boston, Toronto, San Diego: Little, Brown & Co.

Lew, M. (1990). Victims no longer: Men recovering from incest and other sexual child abuse. NY: Harper Collings Publishing.

Lewington, P. (1996). What is the meaning of recovery as lived by persons with traumatic brain injury. Doctoral Dissertation. Vancouver, British Columbia: University of British Columbia.

Lezak, M. D. (1986). Psychological implications of traumatic brain injury for the patient's family. Rehabilitation Psychology, 31, (4), 241 - 246.

Livingston, M. G. (1987). Head injury: The relative's response. Brain Injury, 1, (1), 33 - 39

Livingston, M. G., & Brooks, D. N. (1988). The burden on families of the brain injured: A review. Journal of Head Trauma Rehabilitation, 3, (4), 6 - 15.

Mann, J.L., Chan, S.M., Connell, J.E., & Unander, J. (1988). Developing a trauma recovery group: Understanding the theoretical and practical considerations governing a viable model of emotional recovery for direct and indirect brain trauma survivors. Collected Papers on TBI. Burnaby: Unpublished.

Maitz, E. A., & Sachs, P. R. (1995). Treating families of individuals with traumatic brain injury from a family systems perspective. Journal of Head Trauma Rehabilitation, 10, (2), 1 - 11.

Miller, L. (1992). Back to the future, legal vocational and quality of life issues in the long term adjustment of the TBI patient. The Journal of Cognitive Rehabilitation 10 (5), (pp. 14-20).

Miller, L. (1991). Significant others: Treating brain injury in the family context. Cognitive Rehabilitation, 9, (3), 16 - 25.

Moore, A., Stambrook, M., & Peters, L. (1992). Centripetal and centrifugal family life cycle factors in long-term outcome following traumatic brain injury. Brain Injury, 7, (3), 247-255.

Osborne, J. (1990). Some basic existential - phenomenological research methodology for counsellors. Canadian Journal of Counselling, 24, 79 - 91.

Prigatano, G.P. (1995). 1994 Sheldon Berrol, M.D., Senior Lectureship: The problem of lost normality after brain injury, Journal of Head Trauma Rehabilitation 10 - (3), (pp. 87-95).

Prigatano, G. (1986). Psychotherapy after brain injury. In D.J. Fordyce, H. K. Zeiner, J. R. Roueche & M. Pepping (Eds.) Neuropsychological rehabilitation after brain injury. (Pp. 16 - 31). Baltimore, London: Johns Hopkins University Press.

Rimel, R.W., Jane J. A., & Bond, M.R. (1990). Characteristics of the head injured patient. In M. Rosenthal, E.R. Griffith, M.R. Bond & J.D. Miller (Eds.) Rehabilitation of the head injured adult. (Pp. 8-16) 2nd ed. Philadelphia: F.A. Davis Co.

Rosenthal, M., & Young M. S. (1988). Effective family intervention after traumatic brain injury: Theory and practise. Journal of Head Trauma Rehabilitation, 3, (4), 42 - 50.

Sbordone, R.J. (1984). Rehabilitative neuropsychological approach for severe traumatic brain injured patients. Professional Psychology Research and Practise 15 (2), (pp. 165-175).

Schmidt, J. (1993). Perceptions of traumatic brain injury: Discrepancies between survivors, family members, and professionals. Address to Pacific Coast Brain injury Conference, Unpublished.

Stake, R.E., (1994). Case studies. In Denzin, N.K., & Lincoln, Y.S. (Eds.) Handbook of qualitative research. (Pp. 236-247). London: Sage Publications.

Stevens - Long, J. & Commons, M. (1992). Adult life. Mountain View, CA: Mayfield publishing.

Urbach, J. R., & Culbert, J. P. (1991). Head injured parents and their children's psychosocial consequences of a traumatic syndrome. Psychosomatics, 32, (1), 24 - 31.

Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. London, Ont: The Althouse Press.

Williams, J. M. (1991). Family reaction to head injury. In J. M. Williams & T. Kay (Eds.) Head injury, a family matter. (Pp. 81 - 100). Maryland: Paul H. Brooks.

Zarski, J.J., DePompei, R., & Zook, A. (1988). Traumatic brain injury: Dimensions of family responsivity. Journal of Head Trauma Rehabilitation, 3, (4), 31 - 41.

APPENDIX C

ORIENTING STATEMENT

The researcher will read the first part of the following statement to all participants at the beginning of the first interview. There are two versions of the second part of the statement. Version 1 will be read to the survivor and family member (s) and Version 2 will be read to the treatment professional.

I am interested in learning about what it has been like for you to experience, understand and make sense of traumatic brain injury. There has been very little research which focuses on the experience of survivors, families, and treatment professionals, as they are confronted with and respond to TBI. The research question I am asking is **“How is TBI perceived and meaningfully constructed by a survivor, his/ her family member(s), and a treatment professional responsible for overseeing rehabilitation service delivery?”**

Version 1

I would like you to talk about what the experience of dealing with TBI has been like for you. How have you been affected by this injury? How have you come to understand the effects of the injury and its impact on your life? On what do you base your perception of the injury and the impact it has and may continue to have on your life/the life of your loved one. Please feel free to take all the time you need to think about and answer the questions? During the interview I may ask you for more information or clarification to make sure that I understand your experience. You are not obliged to answer questions or discuss issues you are not comfortable with.

Do you have any questions before we begin?

Version 2

I would like you to talk about what the experience of dealing with this particular TBI has been like for you. I invite you to identify and discuss the personal as well as professional factors you bring to this experience. How have you developed a perception of this injury and its' impact on the survivor. On what do you base this perception? What kinds of factors shape your perception? Please feel free to take all the time you need to think about and answer these questions. During the interview I may ask you for more information or clarification to ensure that I understand your experience. You are not obliged to answer questions or discuss issues you are not comfortable with.

Do you have any questions before we begin?

APPENDIX D

General Research Questions

How is traumatic brain injury perceived and meaningfully constructed by a survivor, his/her family member (s) and a treatment professional responsible for overseeing rehabilitation services.

Interview Question

What has it been like for you to experience, understand and make sense of your (loved one's) TBI?

Additional Interview Questions

1. What was your life/the life of your loved one like before this injury?
2. What is your life/the life of your loved one like now?
3. How did you initially hear about and respond to the fact that you/your loved one had a TBI?
4. What has it been like for you to come to understand/make sense of the TBI and how it has affected you/your loved one's life?
5. Can you describe your current understanding of you/your loved one's TBI, including the impact it has on your life and the impact it may have on you/your loved one's future?
6. What factors have influenced/shaped your understanding?

Questions for Treatment Professionals

1. Can you describe how you came to be involved with this particular case?
2. Can you describe the personal and professional qualities you bring to your involvement in this file?
3. How long have you worked in rehabilitation with TBI survivors and their families?
4. Can you describe your personal rehabilitation philosophy?
5. Can you describe your perception of this injury, specifically the ways in which it impacts the survivor and his/her family now and potentially in the future?
6. On what do you base this perception?