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**MILD TRAUMATIC BRAIN INJURY:  
IMPACT ON IDENTITY AND AMBIGUOUS LOSS IN THE FAMILY**

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**Abstract**

*Research has revealed that almost half of relationships will end in divorce or separation when one member experiences a head injury. Many patients are not diagnosed initially, or for several months or years after their injury. Persons dealing with the numerous long-term cognitive and physical problems accompanying mild traumatic brain injury (MTBI) may develop a profound sense of “loss of self.” This loss of self, manifest as identity ambiguity on the part of the MTBI subject may be strongly correlated with perceptions of boundary ambiguity on the part of the subject and family resulting from the situation of ambiguous loss. Early recognition and intervention may prevent relational and marital breakdown as well as unnecessary distress to family members. This paper discusses the theoretical foundations of our research, preliminary findings of our ongoing qualitative study, and implications for future research and clinical intervention.*

Key words: ambiguous loss; boundary ambiguity; head injury; loss of self; mild traumatic brain injury (MTBI), MTBI and relational breakdown

### **MILD TRAUMATIC BRAIN INJURY: IMPACT ON IDENTITY AND AMBIGUOUS LOSS IN THE FAMILY**

Sara was a 31-year-old intelligent, hard-working speech and language therapist, who had been happily married for several years. While sitting at a stoplight one afternoon, Sara was rear-ended. Treated only for whiplash in the emergency room, she was sent home unaware that any long-term damage had occurred. In the weeks following the accident, Sara began feeling depressed and anxious. She was unable to concentrate and function at work; while at home she was prone to emotional outbursts. Suffering from severe back and shoulder pain during the day, she would also wake in the night with clenched jaw and fists, and severe cramping in her feet and arms. Sara and her husband David were finding it impossible to communicate as they once had and marital stress increased. By the time she sought treatment for Post-Traumatic Stress Disorder (PTSD), the relationship with her husband had drastically deteriorated. Seeing that she was having problems, Sara's parents attempted to help and became increasingly involved in her daily life. Subsequently diagnosed with MTBI as a result of the car accident, Sara began to overcompensate by working more and sleeping less. Feelings of guilt, anger, and resentment intensified in the marriage. As well, Sara and her father would have bitter arguments about her failing marriage while she and her mother would have fights that generally ended in violence. Sara and David were silent about their own feelings surrounding the marriage for fear of hurting or offending each other, or of being rejected. As Sara became more aware of the ways in which the MTBI had affected her life, she began to set more realistic goals for rehabilitation and was hopeful that her marriage could be salvaged. After years of strain and feeling that Sara had become a completely different person, David was unwilling to continue marriage counseling and filed for divorce. Sara and her parents continued to fight and are now struggling to forgive one another and rebuild their family connections.

### **Theoretical Underpinnings**

A number of researchers have explored the effect of traumatic brain injury (TBI) on family relationships (Florian et. al., 1989; Kreutzer et. al., 2002; Laroï, 2003; Perlesz & O'Loughlan, 1998; Resnick, 1993; Tyerman & Booth, 2001; Willer et. al., 1991). TBI is commonly diagnosed by an extended period of loss of consciousness as opposed to Mild Traumatic Brain Injury (MTBI) where there is no loss of consciousness or the loss is brief. Unfortunately, there is as yet no other agreed upon distinction. There is also considerable coverage of the concept of “loss of self” as a consequence of TBI (Dann, 1984; Miller, 1993; Myles, 2004; Nochi, 1997, 1998, 2000; Persinger, 1993; Pollack, 1994).

However, a crucial gap still prevails. There have been no investigations into the combined impact of MTBI on loss of self and identity ambiguity in connection with what Boss (2002, 2004a) terms “boundary ambiguity and ambiguous loss” and their influence on relational breakdown. Ambiguous loss is described as “the most stressful kind of loss,” in that it defies closure. Though the death of a family member is a stressful event, it is validated through socio-cultural processes that allow families to move forward through their grief. Conversely, when a family member disappears, for instance by kidnapping (physical loss) or debilitating illness (psychological loss), remaining family members are thrown into uncertainty. Lacking verification of the loss and thus family membership or social processes, the ambiguous loss, if unresolved, creates the condition of boundary ambiguity within the family system. Families may find it impossible to work through their grief as they have been unable to renegotiate their new social boundaries. In such uncharted territory, a family may become paralyzed, unable to grieve and heal (Boss, 2006).

Common sense would dictate that, in addition to cognitive and physical impairment, MTBI can cause severe disruption in self-image and interpersonal relationships. Unfortunately, this is frequently not taken into consideration during treatment planning or by third-party payers. For many individuals with MTBI, neglect of the emotional and relational aspects of the injury will result in inadequate treatment and considerable, unnecessary suffering.

Long-term presence of psychiatric symptoms is frequently found in subjects who have experienced TBI (Arciniegas et. al., 2003; Brooks, 1986; Fujii, 2002; Koponen et. al., 2002; van Reekum et. al., 1996). Psychiatric conditions commonly observed following MTBI include depression, anxiety, and dissociative disorder (Busch, 1998; Mooney and Speed, 2001). Depending on the circumstances of the injury, people with MTBI may develop acute stress disorder and PTSD (Harvey and Bryant, 2000; Hibbard, 1998; Hiott & Labbate, 2002; Ohry et. al., 1996). This will invariably catalyze relational problems such as marital distress, disintegration of parenting skills, and workplace conflicts. Even when PTSD as a diagnosis is not present, the serious symptoms of MTBI frequently act as major stressors in their own right. These include: cognitive deficits, auditory and visual problems, spatial disorientation, vertigo, balance problems, chronic pain, sleep disturbance, fatigue, headache, toothache, dislocated jaw, endocrinal and neurotransmitter imbalance, depression, anger management problems, unpredictable emotional outbursts, and numerous other physical challenges.

There is clear evidence that the symptoms of chronic illness or pain, such as those listed above, will change the way people relate to themselves and those closest to them

(Campbell, 2003; McDaniel & Doherty, 2003; Rolland, 1994). Similar to Seaburn's description of cancer as the unwelcome guest (1990), families dealing with MTBI may struggle with the realization that the injury has left a stranger in their midst who has become the predominant presence in every conversation and major decision. However, despite the centrality of the topic, many families refrain from talking about their most important issues for fear that discussion will create alienation, blame, guilt and/or rejection. In cases of families dealing with MTBI, MTBI subjects frequently try to hide their deficits while the family "walks on egg shells." The family members may share their concerns and observations with one another, but not with the MTBI subject. This combination of ambiguity and secrecy compounds the problem and is particularly evident in couple relationships.

Our extensive clinical experience with the impact of MTBI suggests that subjects with MTBI frequently develop a sense of loss of self. This loss of self can be attributed to their new physical and emotional deficits that profoundly alter their family and social interactions. As the case of Sara and David demonstrates, this loss can cause a devastating ripple effect not only in couple relationships but within the family system. The sense of loss of self and resulting identity ambiguity experienced by a family member with MTBI creates a sense of boundary ambiguity in both the couple and the family. The boundary ambiguity may manifest as loss of the injured person as the family knew her or him, as well as loss of the family system as it once was. With such ambiguous loss, the boundary ambiguity is left unresolved. These effects clinically appear to be associated with considerable stress, and may correlate with the breakdown of couples, parental and family relationships.

Ambiguous loss has been closely studied in cases of Alzheimer's disease, missing persons in New York after September 11, 2001 (Boss et. al., 2003), and cases of the "disappeared" following political dissension in countries like Argentina and Cambodia (Boss, 1999). In addition, disconnectedness, disruption, and disintegration of family relationships following trauma have been studied extensively (Calhoun & Tendeschi, 1999; Eisenbruch, 1991; Horwitz, 2001; Landau, 2005; Landau & Saul, 2004). Nevertheless, the far-reaching implications of loss of self, identity ambiguity, boundary ambiguity, and ambiguous loss on the family following MTBI have gone largely undocumented. This is an area in which early assessment and intervention could prevent major lifelong personal and relational difficulties. Therapy following MTBI must include the family and all intimate relationships. Long-term cognitive, physical, emotional, and relational losses must be treated in order for the individual to resume personal, family, social, and work functions. It is also of utmost importance that in considering the biopsychosocial aspects of care, the cultural and spiritual components of healing be addressed.

### **Background**

The occurrence of relational breakdown due to brain injury is not dependent on the magnitude of the trauma. A 1997 study by Wood and Yurdakul examined the change in marital status of 131 subjects who had brain injuries of varying severity. All subjects had been married or living with a partner for at least one year prior to the injury. In follow-up, an average of eight years post-injury, it was found that only 39.69% remained married, 3.05% were still in common law relationships, and 2.29% were engaged. Almost half of all subjects, 48.86%, had been divorced or separated. Similar studies with TBI

caregivers have revealed that, not only do the needs of the family change over time (Kolakowsky-Hayner et. al., 2001), but that stress levels actually increase (Perlesz & O'Loughlan, 1998). Tolerance for the injured family member remains high in the initial six months post-injury, often taking several years for negative sentiment to build. Wood and Yurdakul found that the perceptions of the family and injured family member transform with the “watershed for relationship breakdown being about 5-6 years post-injury.” Regarding this breakdown, “the nature of the neurobehavioral sequelae, rather than severity of injury itself, is the important factor” (Wood and Yurdakul, 1997, p. 498).

Early assessment and intervention to prevent relational breakdown in cases of MTBI, requires, first, that the MTBI be recognized, and second, that it be understood as the severe stressor that it is. Unfortunately, many cases of relational breakdown resulting from MTBI do not present with a clear diagnosis or history of head injury. Often, the primary care provider or marriage and family therapist will encounter cases of PTSD, anxiety, depression, and relational breakdown that have developed as the result of a head injury that was never properly diagnosed and treated. In these cases, it is unlikely that patients will offer a spontaneous history of head injury.

In their study of children who have sustained head injury, the American Association of Pediatrics stated that, “MTBI is an evolving process, not a static event,” requiring evaluation on an ongoing basis (2000). However, following a 6-year investigation into evidence for prevention, diagnosis, prognosis and treatment, the WHO Collaborating Centre Task Force on MTBI concluded that, “in the absence of clear evidence, experts frequently disagree. Clear, comprehensive, evidence-based guidelines dealing with MTBI are urgently needed” (Peloso et. al., 2004, p. 110-111).

As MTBI can occur even when there is no loss of consciousness, it is often overlooked following sports injuries (Bailes & Cantu, 2001; Delaney et. al., 2005; Guskiewicz et. al., 2005), and traffic accidents (Cassidy et. al., 2004). Dubbed a silent epidemic,

“Studies suggest that up to 80% of all individuals with traumatic brain injuries are diagnosed as having a mild injury. The number of persons who sustain mild traumatic brain injuries would be much higher, however, if the data included persons who do not require hospitalization. This data, however, is hard to collect. Mild traumatic brain injuries are often called concussions and there is still a lack of education among the general public that a concussion is a brain injury” (Lash et. al., 2004, p. 4).

After one brain injury has been sustained, the likelihood of recurrence is 2 to 4 times greater (AAP, 2000), placing persons at risk for second impact syndrome (Delaney et. al., 2005) or diffuse cerebral swelling (McCrorry, 2001). Compared to someone who has never experienced brain injury, the likelihood of recurrence is eight-fold after the occurrence of 2 brain injuries (Brookshire, 1997). There is definite, “heterogeneity of symptom presentation after MTBI” (Cicerone et. al., 1996: 283). Further, the symptoms of MTBI (e.g., double vision, irritability, memory loss, nausea/vomiting, problems with balance, spatial orientation, concentration, and multi-tasking) may not even become evident until weeks or months post-injury (Chambers et. al., 1996; Clements, 1997; Lash et. al., 2004). Taking these factors into consideration, it can be very difficult for families and therapists to identify relational trouble in connection with MTBI.

Given these findings, we initiated research into the specific impact of MTBI on family, couple, and parental relationships. (Interviews with children under the age of 18 were not permitted by our Institutional Review Board; however, many MTBI subjects discussed the impact their injury has had on their relationship with their children). The current study explores the correlation between the individual's sense of loss of self and resulting identity ambiguity with the family's experience of loss of other, as they knew him or her. This study also explores the relationship between identity ambiguity on the part of the individual with MTBI and boundary ambiguity on the part of the family system and whether these correlate with ambiguous loss. This paper shares preliminary qualitative examples and observations of this ongoing study.

### **Current Study**

#### **Study Aims**

- (1) To explore the relationship between identity ambiguity on the part of the MTBI subject and the partner and/or family's sense of loss of other and boundary ambiguity.
- (2) To explore the correlation of identity ambiguity, boundary ambiguity in this situation of ambiguous loss.
- (3) To explore whether MTBI results in relational breakdown and subsequent separation or divorce because of ambiguous loss.

#### **Hypothesis**

In the situation of systemic ambiguous loss due to MTBI, the higher the perceptions of identity ambiguity on the part of the MTBI subject and boundary ambiguity on the part of the partner and/ or family the higher the incidence of relational breakdown and subsequent separation or divorce.

#### **Method**

*Participants.* Though all subjects are at variable post-injury intervals, all are 18 years and older and have been previously diagnosed with MTBI based on DSM-IV and/or ICD-10 criteria for Post-Concussive Syndrome. Additional diagnostic measures may include some or all of the following: Neuropsychological Symptom Checklist, Personality Assessment Inventory, Functional Symptom Questionnaire (Keatley, 2000), and selected subtests of the Halstead-Reitan, WAIS III, Wechsler Memory Scale III, and Woodcock-Johnson III. Subjects are invited from a client base of 5 area practices and are encouraged to invite 2 or more adult family members to participate in the study.

*Qualitative.* Three open-ended interviews are conducted, one with the subject alone, one with the family members without the subject (spouse, partner, parents, and adult children), and one with both the subject and family member participants. Questions are directed towards enhancing our understanding of the interface of the subject's experience of loss of self and identity ambiguity and the family's experience of loss of other and boundary ambiguity. Questions also explore whether these phenomena are associated with the condition of ambiguous loss. Subjects and family members are asked to describe their relationships pre- and post-trauma and diagnosis. Subjects are asked to describe their sense of self and their relationship with family members. Family members describe their relationship with the subject and the family. With written and verbal consent, the interviews are recorded and subsequently transcribed. Specific comments relating to breakdown of relationships, perceived criticism, boundary/identity ambiguity, secrecy, and family/subject grief from loss are identified and coded. This type of

qualitative research with small groups has proven very effective in previous studies of ambiguous loss (Boss, 1999; 2004; 2006), and loss of self following brain injury (Nochi, 1998, 2000). By allowing families freely to discuss their experiences, they are able not only to give voice to a silent epidemic, but also to provide, “rich detailed concerns and suggestions upon which clinical interventions can be grounded” (Tubbs & Boss, 2000, p. 285).

## **Results**

*Loss of Self and Identity Ambiguity.* All MTBI subjects interviewed have described feeling a loss of sense of self accompanied by a change in self-image, increased self-doubt, and decreased confidence following their injury. These symptoms match what Nochi found in his groundbreaking work with subjects who had experienced TBI,

“Narratives of people with TBI suggest that the experience of loss of self is not monolithic but able to take various forms. This diverse nature of loss of self seems to reflect the complexity of the self. Theorists have recognized that the self is constantly generated and modified in the person’s interaction in the world” (1998, p. 875).

Nochi further directs his analysis towards individual narrative and three categories of loss: loss of clear self-knowledge, loss of self by comparison, and loss of self in the eyes of others. We have found that in the case of MTBI these losses often operate concurrently and are major players in both individual and family narratives, as is illustrated by the experiences of Karen, described below.

At 55, Karen was a confident and vibrant woman who had success and joy as a sales manager, published author, musician and avid traveler. Through her determination and inherent “grit” as she describes it, Karen was able to survive four different forms of cancer in four years and regain her health. One afternoon in highway traffic, she was a passenger in a car that was struck from behind at 50 mph. She sustained multiple injuries and was diagnosed with PTSD and MTBI.

“My cancers were real. Something I had to deal with. What I am experiencing now, since the car accident, is worse than those cancers ever were. This auto accident took away who I was. My brain worked just great before, during and after my cancers. But after this car accident, my brain is not like it was before the car accident. I am a different person...I have lost my sense of self and my competency. I miss my independence and ability to be a significant contributing member to society, service to others and financially to my family...I feel that I am unable to give to my family and friends the way I once did...I am most saddened by the fact that I am no longer able to help others like I was once able to do.”

The loss of confidence and self worth that accompanies the loss of sense of self is strongly connected to feelings of identity ambiguity and inadequacy regarding role fulfillment within the family. All MTBI subjects interviewed have reported feeling very guilty about their new “diminished” role in the family or partnership. Whether no longer capable of being the breadwinner in the family or forgetting to put gas in the car or collect the children from school, subjects are invariably troubled by the inability to meet their own expectations and the expectations of others. Many become distraught.

Tim was a 45-year-old professional addiction counselor who had been married for 15 years. After Tim was hit from behind while stopped at an intersection, paramedics assessed his injuries and told him he was fine. Still feeling “not quite right,” Tim drove

himself to the emergency room where doctors also said that he was fine. In the weeks that followed, he began to experience auditory and visual problems, and an inability to multi-task. Tim also felt emotionally labile. Later diagnosed with MTBI, he has encountered many people with the same diagnosis who share his experience.

“I think the most difficult thing is getting people to understand the impact of what has happened to you on your life. They [MTBI subjects] all have this sense of isolation, they all have this sense of rejection, they all have this sense of being pigeonholed as a malingerer. They all have these frustrated relationships that they’re in. What this does is it brings out the worst in people. Your defenses are down, the other person gets more and more angry, you get angry, and then because your filters are down you’re no longer able to absorb and contain the things so you can process them. It certainly affected my last marriage, my wife kept thinking I was malingering and she wouldn’t come to therapy because she was so disgusted with how I was behaving. Breaking stuff all the time and I’d ask her the same question over and over again. It got to the point where I was recovered enough that I just said I had enough. Some people say I’m much different, and I feel I’m much different and I also have had to change the way I deal with things. I do want to be in a relationship, but I’m not sure what I want to offer, or have to offer anymore.”

Tim’s experience with his wife’s anger at his supposed malingering is not uncommon. A sudden change in behavior, as Tim’s wife observed with him, can seem inexplicable. Family members, trying to make sense of the change, frequently attribute the cause to such things as malingering, deliberate obstruction, or laziness. This further compounds the problem because, like Tim and the rest of his family, they are unaware of the real reason for the change or how to mend the situation. Family members are driven towards silence because talking does not seem improve the situation.

When the role and identity of one family member are in question, the family system may be thrown into disorder. This asynchrony in pace and direction within the system invariably creates symptoms of stress in the subject and/or the family, resulting in transitional conflict (Landau, 1982). While this conflict is an opportunity for positive change (Byng-Hall, 2004), this type of transition in the family structure generally does not occur when the “participants are psychologically or relationally ready” (Wynne, 1998, p. 81). This is particularly true of family transitions regarding MTBI, where the disruption is sudden, visually not apparent, misunderstood and often undiagnosed.

*Boundary Ambiguity.* As the MTBI subject experiences increasing identity ambiguity, the family experiences increasing boundary ambiguity. A renegotiation of the MTBI subject’s personal and family boundaries becomes imperative, though over-riding feelings of confusion, loss, anger, depression, resentment, frustration and guilt, compounded by secrecy, make it difficult to know where to begin. Many MTBI subjects have reported a huge “disconnect” between the people they present to the world, versus whom they feel they’ve become inside. They have also discussed “shutting down” emotionally in response to their physical and psychological pain leading to the family being unable to interpret their reactions and responses. Cognitive problems, and auditory and visual loss and filtering problems, further aggravate the MTBI subject’s sense of distance and unreality, causing subjects to withdraw socially and, in some cases, exacerbate previously resolved addictions and disorders. Formerly social MTBI subjects

have discussed “wanting to hide out from everyone,” no longer wanting to attend any type of social gathering, finding that the noise levels, required communication, and focus are too exhausting. These create a sense of distance in the family thereby increasing the boundary ambiguity.

In several of our cases and very commonly with MTBI, this is accompanied by a reduction in sexual drive caused by injury to the hypothalamus and other hormonal imbalance. Many MTBI subjects and family members feel a need to protect each other and themselves from the full impact of their concerns. This results in secrecy about issues that need to be expressed and dealt with in order for boundary ambiguity to be resolved. For partners and family members of MTBI subjects the combination of all these factors can feel like outright rejection. As Peter and Laura’s case illustrate, the increase in Peter’s identity ambiguity diminished their ability to understand one another and exacerbated the boundary ambiguity.

Peter and Laura were in their mid-thirties and had been married only a month when Peter sustained a head injury. Shortly after the accident he began suffering from acute anxiety and PTSD. Unable to keep his own business but still wanting to take care of Laura, Peter took a technically demanding job that increased his stress and added to his chronic exhaustion. Peter was frustrated with his short-term memory loss, cognitive deficits, mood swings, sleep disturbances, and dependency on his wife. Laura was increasingly worried by his personality change and desire to be alone. Both were thoroughly committed to Peter’s rehabilitation and recovery, though this consumed so much of their energy that the intimacy and fun were drained from the marriage. Communication became very difficult and they argued frequently. Despite Laura’s support, Peter was still saddened by the loss of his business, his sense of self, and the future they had planned together.

Many of the families we interviewed initially responded with great tolerance of the MTBI subject’s anomalous behavior. Following a car accident for example, partners and family members assumed greater responsibility for assisting the subject with rehabilitation and assuaging the turmoil of the unfamiliar situation. This willingness to undertake additional household chores, financial support, and errands was often done out of love as well as necessity, and with the assumption that it would be a short-term solution. During the early phase, roles and relationships tended to remain unambiguous. However, when the MTBI subject’s rehabilitation did not conform to the family’s preconceived timeline, temporal boundaries became blurred. Ambiguity began to permeate both the present and future identity of the entire family, tolerance was reduced, impatience grew, tempers became frayed, and relationships at best were strained. At worst, boundary ambiguity resulted.

In some families we found that a diagnosis of MTBI, either in conjunction with PTSD or not, helped to reduce this ambiguity. It gave MTBI subjects validation; finally someone in the medical community was able to give a name and reason for their private distress, it was no longer just “in their head.” Though the problems did not disappear, the diagnosis served as a relief for family members as well. They could also point to an organic problem instead of agonizing over the erratic stranger in their midst and wondering when their loved one would “get back to normal.” Sometimes a diagnosis of MTBI was not met with acceptance. Some MTBI subjects were embarrassed by the “brain injury” label and attempted to conceal it from friends and family. In a few cases

this fear of stigmatization caused denial and disbelief by partners and spouses, creating major obstacles to communication and healing.

Unfortunately, it has been our experience that many MTBI sufferers go without proper assessment and diagnosis. Despite repeated requests for assessment when concerned that something was wrong, many subjects had initially been told “not to worry” because they “will recover soon.” This misinformation causes the family to set their expectations too high, compounding the individual’s feelings of frustration and helplessness. MTBI subject’s identity ambiguity increases concurrently with boundary ambiguity on the part of the family.

The lack of proper medical diagnosis can also exacerbate an additional set of problems: Many persons with MTBI encounter serious legal issues. Most of the subjects in our study acquired MTBI as the result of car accidents that had rendered them financially drained and unable to work. They described their subsequent interactions with insurance companies and lawyers as “frustrating and demeaning.” MTBI subjects have described feeling further isolated as their problems were marginalized by the medical community, the court system, and their families. This is largely because, “the burden of proof can be very difficult to meet for an invisible injury which is not well understood by science and which is subject to the worst of human prejudices” (Webster, 2000, p. 19).

Stern expands on the notion of prejudice and the social implications of brain injury;

“Our civil justice system, however, is nothing more than a microcosm of society at large. The biases encountered by individuals with acquired traumatic brain injury in the civil justice system are no different than the biases in many instances this population encounters in many aspects of their ordinary lives... Health care benefits for those with TBI are limited and inadequate. Insurance disability carriers pigeonhole those with these disabilities often times as mental or psychological claims, limiting the extent and duration of disability payments. Because TBI truly is the silent epidemic, those with this injury have, in the past, been severely discriminated against in various aspects of life. The civil justice system is no different” (1995).

The lack of understanding surrounding MTBI can lead to discrimination that further isolates individuals, causing greater confusion, conflict, and boundary ambiguity within the family system. The MTBI subject’s identity ambiguity may be further increased by the conflicting drive to become healthy and the unconscious pressure to remain incapacitated in order to prove their case. These cases, which can continue for several years, can become barriers to healing, causing tremendous stress and acrimony within relationships. This is aggravated by the lack of knowledge of the timelines for healing and recovery, and whether individuals with MTBI, such as Peter and Karen, will “return to normal.”

*Renegotiating Boundaries vs. Returning to Normal.* Like Peter and Laura, Adam and Karen had only been married a short time when they realized the extent of her injuries. As the combination of PTSD and MTBI made it impossible for Karen to work, Adam assumed all financial responsibilities including house and car payments, legal fees, and medical bills. Offered a lucrative out-of-state job, he had to decline as Karen would be unable to leave her treatment team and Adam was reluctant to leave her. Plans for travel and adopting children had to be set aside indefinitely. Karen felt guilty and undeserving of Adam, saying that she would not have married him if she knew she was

“going to be this bad.” In his adolescence, a cousin of Adam’s had suffered a brain injury. He described watching as his cousin changed completely within a few months of the accident, going from first in his class to dropping out of school. He recalled his cousin's family responding with anger, intolerance, and verbal abuse to what they perceived as the cousin’s apathy. As a result of this experience, Adam has been tireless in his determination to convince Karen that she is not a burden. He strongly believes that she will “return to normal” in six to seven years.

There is still work to do, since “returning to the person she was” is not necessarily the best outcome for which to hope, as it might well be unrealistic. This idea has gained leverage in the rehabilitation community where there has been advocacy for a paradigm shift; patients are increasingly encouraged to set goals for “who they want to become,” instead of attempting to recapture the past (Maitz et. al., 2000). As Dijkers points out, the inherent snag in this approach is that a deliberate shedding of the “old self” will intensify the existing sense of loss of self (2004). Many families dealing with MTBI need to be encouraged to work towards finding their new joint reality with its own strengths and resilience so that they may move forward together with more certainty, clarity, and realistic expectations, and less ambiguity and false hope.

Karen and Adam came from different cultures and spoke different languages: Prior to the injury, they had communicated in English, though it was not Adam’s mother tongue. Karen’s cognitive deficits increased this communication difficulty, and for several months their frustration at the situation caused many arguments. This communication problem is also common in couples where there is no cultural contrast. Adam and Karen spoke about renegotiating their marriage and their communication style so that they could continue to function. Adam revealed that the most effective approach he had found was “getting involved through strategic thinking.” Things improved between them when he started attending doctor’s appointments with her. He has also learned to recognize the best times of day for her, and often reminds her of things she must get done and when she needs to rest. The two also spoke about the strength they feel through their shared spirituality and ability to give each other space. Karen has stated that Adam is, “a generous person with healthy boundaries.” The two are very excited about learning a new language together and planning trips for the future. They seem to have established a sustainable situation by actively reconstructing the boundaries of their relationship and the picture of their future together.

*Common Biopsychosocial Themes of Survival and Resilience.* Given the magnitude of the problems associated with MTBI, it was inspiring to hear stories of resilience and survival, from the MTBI subjects, their partners, and other family members. We divided these stories into two primary themes: (a) Collaboration and Integrated Care, and (b) Identity Reconstruction.

(a) Collaboration and Integrated Care: Though struggling with a variety of physical problems, all MTBI subjects discussed the importance of a “mind-body-spirit” approach to healing. In addition to the need for a physical “re-balancing,” they stressed that integrated care and collaboration among practitioners was essential. Though common problems associated with brain injury include cognitive, visual, auditory, endocrine, neurological, orthopedic, urological, and digestive problems, there are some injuries fairly typical of MTBI of which many practitioners are unaware. For example, most of the subjects had experienced jaw dislocation resulting in serious tooth injuries, TMJ, and

severe neck pain that had taken many months to diagnose until someone had sent them to a TMJ dental expert. This injury had kept them awake at night, aggravating their nightmares, increasing chronic pain from cervical disk lesions or other chronic neck injuries, precipitating episodes of PTSD, and upsetting their bed partners who were also becoming sleep deprived and irritable.

Some subjects had problems with incontinence, impotence, menstruation or the recurrence of “hot flashes” that they had been too shy to mention to their partners or providers. Some subjects were still driving, despite their reduced vision, vertigo, and PTSD. Others had partners who refused to keep driving them, or who could not afford taxis or drivers. Most were unable to dine in restaurants for many months or years because of their problems with auditory discrimination, and/or hyperacusis in combination with hearing loss. For many subjects, these problems were aggravated by severe financial hardship that further complicated both the individual and relational picture, limiting access to solutions and treatment options. All of these problems and many others proved to be physically, socially, and relationally incapacitating.

When their problems were treated in isolation, subjects described feelings of helplessness. Addressing each problem as a tiny carved up “organ” segment left them trying to solve an impossible larger puzzle. Subjects felt a major shift in their healing when one practitioner took responsibility for coordinating the team and providing true biopsychosocial collaborative care. If the patient had originally been referred for assessment, this person was typically the primary care physician or neurologist. In the case of individual psychological problems, relational conflict, or cognitive issues the practitioner was either the family or cognitive therapist. This latter category included most of our subjects. Given these findings, it would be useful for cognitive therapists to receive systemic training to assist them in serving their MTBI clients.

(b) Identity Reconstruction. Many researchers have found that individuals with brain injury are able to re-conceptualize the manner in which the injury has affected their lives. What is initially perceived as a grave loss can actually become something like a blessing in disguise. Subjects report increased appreciation for life, as well as decreased self-destructive behavior (Bogan et. al., 1997; Nochi, 2000). Similarly, many of the subjects we spoke with felt greater compassion and a newly formed dedication to holistic health. Three of the women we spoke with discussed their belief that MTBI has been a “personal growth experience” and spiritual gift that has enabled them to reach the “other side” and develop a new level of compassion and understanding. One subject, a drug-addiction counselor, described increased compassion, tolerance, and patience with his clients. Even when relationships with spouses were deteriorating, some subjects described forging better relationships with their children.

This recalibration in the way MTBI subjects view themselves, their injury, and others is certainly vital to the healing process. It may be due to the actual observation of positive outcomes from the injury, or the very human need to make meaning from an event that is otherwise horrific and seemingly meaningless. In either case, subjects feel that they have gained something despite, and because of, overwhelming loss. Boss (2006) has observed this link between meaning and ambiguous loss. This type of adaptation in populations of trauma survivors and persons with chronic illness has also been examined within the context of response shift theory (Sattler, 2002; Sprangers & Schwartz, 1999). Likewise, conservation of resource theory (Hobfoll, 1988, 1989) proposes, “People strive

to obtain, retain, and protect that which they value.” After a major trauma or under severe stress, families and communities are able to access “hidden reserves” that serve to strengthen individuals and families creating the perception that resources have been enriched (Landau & Saul, 2004, p. 291; Landau & Weaver, 2006). The same dynamics appear to be applicable in relation to MTBI and might prove to be a useful area for future research.

Many of the MTBI subjects we spoke with credit their most profound resilience to a sense of new self-discovery or creation. The development of the “new self” stems from new or renewed connections to the self and others, as well as amelioration of physical and psychological pain. This recalibration and renegotiation of personal and family boundaries assumes many forms. MTBI subjects have reported the achievement of positive results when they felt they were given time to heal, were able to sleep restfully, learned to set reasonable goals, and made specific time for relaxation and leisure with their partners and family members. MTBI subjects have commonly described resilience through humor, love, spirituality, religion, nutrition and exercise, meditation and time alone with nature.

“I don’t want to do any more damage, enough damage has been done. I just try to be thoughtful and as careful and compassionate as I can be and just hope that people will do the same. I’ve taken to riding my bike a bunch, and trying to be more healthy—I quit smoking. It gave me confidence, and an attachment to my body that I didn’t have before.”

“I make jokes about everything. I compensate for my pain, brain glitches and my limitations, through humor. Humor is a way for me not to feel so helpless and out of control, or become a complaining, nagging or difficult person to be around...[it] was and is the way I keep myself from being overwhelmed, sad, angry, or stuck in depression and frustration.”

“I’m less serious now... You go to different landings on a long flight of stairs. You just have to try laugh about just about everything, and make it a joke, because if you don’t, it’s too stressful, too sad, too much loss to do it the other way. And one can really wallow in that sadness.”

### **Implications for Clinical Practice, Training, and Future Research**

The concept of ambiguous loss provides a perspective on MTBI that is highly relevant to the practitioner dealing with MTBI. To date, most research, clinical practice, and training has focused on the individual, not recognizing the devastating impact of MTBI on family relationships. The study findings are of particular significance for family therapists and primary care providers as they are in the unique position of recognizing cases of MTBI that previously have been overlooked. The ambiguous loss framework reveals the importance of including families in the treatment of MTBI subjects. In the absence of an MTBI diagnosis, practitioners should keep this in mind when presented with cases of PTSD, depression, anxiety, or relational stress. It is always worth asking whether there has been any degree of head trauma. This is an area in which early assessment and intervention could prevent major lifelong personal and relational difficulties. Of course, this necessitates that MTBI be recognized and understood to be a serious stressor that is likely to threaten the long-term wellbeing of both individual and family. While the neurobehavioral sequelae and relational difficulties due to MTBI will not be halted through diagnosis, the specific problems associated with brain injury cannot

properly be treated out of context.

Ultimately, families will create their own resilience and define their own future. However, this untimely transition can be eased when ambiguity, fear and secrecy are minimized. If family members are unable to share their hurt, anger, blame, shame and guilt, feelings of sorrow and loss develop across the family system. If these are not discussed and resolved, family members start to withdraw. The situation is aggravated by the family's incapacity to grieve the "missing" person who is still very much present. As the intensity of the situation escalates, boundary ambiguity across the family system results. This is very difficult to resolve in the absence of professional intervention, and typically appears to end in relational breakdown.

The negative impact of ambiguous loss can be prevented by early minimization of the boundary ambiguity (see Boss, 2006, for guidelines). Families need to be encouraged to discuss their feelings and to help the individual learn to accept the differences caused by the MTBI without inducing self-blame and guilt. Reality testing is essential, but needs to be done with constant reassurance. Family members, work colleagues and friends can be educated to become aware of the details and ramifications of the problems. They are then able to help the individual recognize when these occur, while providing constant reassurance of affection and, when appropriate, love, despite the changes everyone has experienced.

Another key factor in the resolution of boundary ambiguity appears to be the amount of effort expended by the support system on remediation of the deficits. (This is in addition to the efforts of the collaborative treatment team.) Members of the support system need to communicate clearly about their observation of losses and changes in the individual. They need to work with the injured individual to find ways to compensate while constantly providing reassurance that the individual is not a burden to anyone and that, regardless of the outcome, there will always be a place for him/her. If this work is done, it seems to be realistic to expect that the individual with MTBI will recover sufficiently to reassume his/her place in the family, if not in the workplace. However, if the work is not done, this is unlikely to happen and relational breakdown appears to be inevitable.

Given the propensity to prevent ambiguous loss, it is clear that it is critical to institute family therapy as soon as possible after an episode of MTBI. The problems associated with MTBI are diverse and debilitating and require specialists in cognitive, emotional, relational, physical, cultural and spiritual areas related to MTBI. Further, the best treatment is provided when these specialists practice in collaboration, rather than splintering the care and further stressing patient and family. Patients who understand their problems can take an active role in their own recovery, so sharing information with patients and families is crucial.

When therapists working from a systemic perspective facilitate patients having the support and acceptance of their families, rehabilitation and recovery can only be enhanced. Regenerating confidence, reconstructing identity, building tolerance for ambiguity in the family system, identifying resources, and fostering support and acceptance are issues for the unique capabilities of the family therapist and/or family practitioner. This is an area where adequate training of primary care providers and family therapists is required. Training should incorporate skills for collaborative care through referral, assessment and early diagnosis.

The wide reaching effects of MTBI are an untapped area for future research. There is still a great deal to be learned about the impact of brain injury at the interface of individuals, families, communities, and healthcare systems. In light of our preliminary findings, that the individual sense of loss of self and identity ambiguity increase the boundary ambiguity within the family, we plan to continue our current research. By further investigating the experiences of those dealing with MTBI, we may better understand its impact on identity and boundaries within the context of the family. This will further aid in the discovery, development, and enhancement of effective methods for prevention of relational breakdown. By applying the theoretical framework of ambiguous loss we hope to increase awareness of MTBI and expand the scope of recovery services.

### **Conclusion**

For many patients and families, one of the most difficult aspects of dealing with MTBI is the disintegration of intimate relationships and ambiguous loss. Some families find themselves in therapy offices or divorce hearings with no realization that their relational problems are attributable to MTBI. Neglect, often unwitting, of the emotional and relational effects of MTBI by healthcare providers and third-party payers can lead to inadequate treatment and considerable, unnecessary suffering for patients and families.

Losses that defy closure are a major aspect of MTBI that should not be underestimated. Because some of the most painful losses in MTBI are intangible, they are often not validated for subject or family. While the loss of self, memory, patience, control and confidence are discrepancies that are most severely felt, they are also the most difficult to substantiate, articulate and regain. They are also the ones least talked about within families. This experience may best be understood by Boss's concept of "ambiguous loss" operating within a systemic process.

The situation of ambiguous loss within a family from the stress of the MTBI prevails as a constant variable in their relationship. The sense of loss of self and resulting identity ambiguity experienced by the individual with MTBI appears to be accompanied by the perception of boundary ambiguity by the entire family. This may be explained by the transitional conflict that arises from the discrepancy of pace and direction in family member responses to MTBI. The boundary ambiguity manifests as the loss of abilities, roles, responsibilities, and identity of the injured person as the family knew him/her, as well as the loss of the family system as it once was. This dynamic is seriously compounded by the presence of secrecy as family members refrain from talking about potentially painful topics. When the family (through no fault of their own) is unable to resolve the ambiguous loss, greater boundary ambiguity often results. Boundary ambiguity appears to be associated with considerable stress, depression, and relational conflict (Boss 1999, 2006). Based on our clinical observations, boundary ambiguity also appears to correlate with the breakdown of couples, parental, and family relationships. We contend that it is essential that MTBI subjects, their partners, and family members receive early, if not immediate, family systems therapy to prevent the devastating consequences of ambiguous loss.

Therapy following MTBI must include the family and all intimate relationships. In order successfully to resume personal, family, social, and work functions, treatment should incorporate all of the long-term cognitive, physical, emotional, and relational losses (both apparent and ambiguous). Ideally, the treatment team should comprise a coordinating clinician and the following modalities and services: primary care;

neurology; family therapy; cognitive therapy; vision therapy; physical therapy; dental, periodontal, and orthodontic services; occupational therapy; organizational skills; and workplace retraining (including, when needed, hand therapy and ergonomic rehabilitation), pain management and trauma relief, e.g., acupuncture, meridian-based techniques, meditation, and holistic body work including massage, Reiki, Shiatsu, Pilates, Feldenkrais, and cranio-sacral massage. This team needs to function collaboratively, and, where possible members should have a modicum of understanding of systems principals and collaborative care. When possible, training in family systems as they relate to MTBI is useful. We have found it most useful to establish a team for this purpose and to hold regular team meetings for mutual collaboration and education. These meetings can occur via teleconference when needed. Team members need not belong to the same service or work under one roof, although this is helpful to MTBI patients who have trouble getting around. It is helpful to identify a single team member to be the primary coordinator with the legal, insurance, and social welfare systems as needed.

It is of the utmost importance in considering the biopsychosocial aspects of care, that the cultural and spiritual components of healing also be addressed with MTBI patients and family. The physical, psychological, financial, legal, and social devastation experienced by individuals and families could be greatly minimized by implementing training designed to increase MTBI awareness and broaden the collaborative skills of clinicians. Early assessment, diagnosis and intervention by a collaborative intervention team including family systems therapy, can effect major change in reducing patient and family suffering, preventing relational breakdown, and minimizing psychotherapy and legal costs and consequences.

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