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The impact of mild traumatic brain injury on romantic relationships

Rylie K. Power
James Madison University

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The Impact of Mild Traumatic Brain Injury on Romantic Relationships

An Honors Program Project Presented to
the Faculty of the Undergraduate
College of Health and Behavioral Studies
James Madison University

by Rylie Kaitlin Power

May 2016

Accepted by the faculty of the Department of Health Sciences, James Madison University, in partial fulfillment of the requirements for the Honors Program.

FACULTY COMMITTEE:

Project Advisor: Audrey J. Burnett, Ph.D, CHES
Associate Professor, Department of Health Sciences

Reader: Felix Wang
Associate Executive Director for Strategic
Partnerships, Office of International Programs

Reader: Cynthia R. O'Donoghue, Ph.D., CCC
Professor and Head, Communication Sciences and
Disorders

HONORS PROGRAM APPROVAL:

Reader: Stephanie L. Baller, Ph.D.
Assistant Professor, Department of Health Sciences

Bradley R. Newcomer, Ph.D.,
Director, Honors Program

PUBLIC PRESENTATION

This work is accepted for presentation, in part or in full, at the JMU Honors Symposium on April 14, 2016 .

Dedication

I dedicate this thesis to my parents, Jeff and Jodi Power, whose world was rocked by my mother's mild traumatic brain injury in 2003. Their unwavering love, strength, and resilience through the acute and long-term recovery process inspires me personally and professionally.

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Abstract

Well-documented symptoms of traumatic brain injury (TBI) include acute symptoms such as headaches, dizziness, blurred vision, nausea, and memory loss. However, many TBI survivors also experience changes in cognition, behavior, personality, and mood that challenge interpersonal relationships. These *invisible*, neurobehavioral symptoms are uniquely challenging for survivors and caregivers of mild TBIs that lack physical, daily reminders that can accompany more severe injuries. The present study focused on the effects of survivors' mild TBIs on their romantic relationships and the potential for a deteriorating support system. A convergent parallel mixed methods approach quantitatively assessed the environment of romantic relationships after brain injury via questionnaires (n=41), while qualitatively seeking to understand couples' reactions to that environment as well as strategies used to adapt to that environment via interviews (n=4). Results confirmed a decrease in relationship satisfaction pre- to post-injury ($p < 0.001$), while also indicating a greater cynicism from caregiving partners. Interviewed participants shared experiences falling into themes of: changes in self (survivor), effect on the relationship, strategies, discontent with resources, and advice to future couples. Understanding the complex, ambiguous experience of a romantic relationship affected by brain injury is essential for professionals to comprehensively treat and for couples to comprehensively recover.

Chapter 1: Introduction

Traumatic brain injury (TBI) diagnoses have skyrocketed within the last decade. Since 2001, emergency department visits, hospitalizations, and death rates have increased from 521 to 823 per 100,000 of the US population (Centers for Disease Control and Prevention [CDC], 2014). The CDC (2010) has estimated that 1.7 million people sustain TBIs every year in the United States, and 5.3 million Americans are living with a long-term disability as a result of TBI. Furthermore, this number increases exponentially when considering the collateral impact upon family and friends of individuals having sustained TBI. In the last several years, TBI has been referred to as an epidemic and a chronic condition, due to its incidence rates and long-term effects on individuals' lives (Vaishnavi, Rao, & Fann, 2009). Similar to other chronic conditions, TBI affects the family unit as a whole, and romantic partners tend to assume the role of caregiver to the injured partner (Blaise & Boisvert, 2005). Awareness of caregiver stress and the relational strain unique to this injury must be acknowledged and addressed in the comprehensive rehabilitation of a TBI survivor.

A traumatic brain injury is defined as an alteration in brain function as a result of an external, mechanical force. Well-documented symptoms of TBI include headache, dizziness, confusion, blurred vision, nausea, and memory loss. However, personality changes that result, and how those changes affect interpersonal relationships, are often overlooked or not discussed in clinical settings or the literature. Some symptoms may lessen throughout the years of recovery and purposeful rehabilitation. Other symptoms, including behavior and mood changes, difficulty with memory, concentration, attention, initiation, logical reasoning, irritability, and agitation are more likely to persist lifelong and hinder loved ones along the way (Joseph, et al., 2015).

Statement of the Problem

Caregiving partners often assume the injured partner's roles and responsibilities (e.g., managing finances, household chores, parenting). This shift, combined with unemployment, expensive therapies and treatments, weigh on the relationship. The implications of these changes - or symptoms - are grossly illustrated by the significant difference between divorce rates of the general population and those following a TBI. Since 1980, the comparative average rate of post-injury divorce has increased from 50% to 78% (Kreutzer, Marwitz, Hsu, Williams & Riddick, 2007). Together, the injury experience and coping with personal changes redefine a TBI survivor's self-identity. For individuals in romantic relationships, the survivor is no longer the same person to whom his or her partner committed.

Traumatic brain injuries are often referred to as *invisible* injuries, because symptoms persist long after physical, external wounds have healed. Specifically, mild traumatic brain injuries are the least likely to have accompanying scars, speech impairments or other physical effects (Joseph, et al., 2015). Personality changes and *invisible*, neurobehavioral symptoms create lasting effects and are uniquely challenging for survivors and caregivers of mild TBIs that lack physical, daily reminders that can accompany more severe injuries. Individuals interacting with survivors often have a difficult time adjusting to persistent changes they cannot see or comprehend, straining those interpersonal relationships.

Significance of the Study

The present study aims to identify typical changes that occur within romantic relationships following a partner's TBI, and to find effective strategies for coping with, adjusting to, and overcoming these changes. The retrospective perspective from experienced couples will

be highlighted as a unique addition to the literature on neurorehabilitation. The purpose of this pilot study is for the findings to become a resource for clinicians and future couples affected by TBI to reference throughout the healing process.

Terms Defined

- Mild Traumatic Brain Injury (mTBI) – an alteration in brain function, or dysfunction, as a result of an external, mechanical force; yields a Glasgow Coma Scale score of 13-15; loss of consciousness and/or disorientation lasting less than 30 minutes, if at all; MRI/CAT scans are typically normal, while patient still presents cognitive problems.
- Romantic relationship – an inclusive term to refer to any two people engaged in a romantic, intimate partnership.
- Survivor – the partner who sustained a TBI.
- Non-injured partner/caregiver – the partner who did not sustain a TBI.

Chapter 2: Literature Review

As more attention is directed to the severity of symptoms and risk for lifelong effects, medical professionals, athletic coaches, parents, and community stakeholders are becoming more aware of and involved with TBI prevention and identification. However, despite improvements in identification, true incidence rates are still estimated to be two to three times greater than reported (Khan, Baguley & Cameron, 2003). On average, it is estimated the majority of brain injuries not reported are milder injuries for which medical attention is not sought (Gennarelli, et al., 2005).

The forces that cause TBIs can be differentiated into contact forces and inertial forces. Contact forces injure the brain by damaging the brain surface (e.g., contusions, hematomas or lacerations). Contact injuries result from the brain coming in contact with either the skull or another object and usually manifest as more focal injuries. Inertial brain injuries damage blood vessels, tear axons or cause intracerebral hematomas as a result of acceleration or deceleration forces compressing brain matter. Inertial forces usually produce more diffuse damage in comparison to contact forces. Most traumatic brain injuries result from a combination of both forces and may present symptoms of both focal and diffuse damage (Gennarelli, et al., 2005).

Traumatic brain injuries are generally classified as severe, moderate, or mild, and are assessed initially using the Glasgow Coma Scale (GCS) and anecdotal evidence (Joseph, et al., 2014). A TBI is categorized as mild with: (1) a GCS of 13-15; (2) any loss of consciousness lasting less than 30 minutes, (3) any loss of memory for events immediately before or after the incident with post-traumatic amnesia lasting less than 24 hours; (4) any alteration in mental state at time of injury (e.g., feeling dazed, disoriented); (5) or focal neurological deficits (Esselman & Uomoto, 1995). Mild TBIs account for 70-85% of hospital visits for TBI, but constitute an even

larger proportion of all TBIs when considering those who did not receive a medical evaluation (Esselman & Uomoto, 1995; Khan, Baguley & Cameron, 2003).

Deceptively termed, mild TBIs can present lifelong cognitive, somatic and emotional symptoms that permeate all aspects of survivors' lives. Following injury, mild TBI survivors most often experience immediate symptoms of headaches, dizziness, fatigue, nausea and irritability, difficulty with concentration and memory, disturbed sleep patterns, vestibular irregularities and light and noise sensitivity (King & Kirwilliam, 2011; Khan, et al., 2003). These physical symptoms are more likely to decrease over time, but can persist and interfere with the survivor's daily functioning. Neurobehavioral effects are even more likely to produce long-term challenges (McAllister, 2008). The most salient neurobehavioral symptoms include those associated with cognition, behavior and personality. Cognitive symptoms are often identified as difficulty with executive functions, such as problem solving, impulse control and self-regulation, speed of information processing, diminished attention, and short-term memory. Personality and behavioral symptoms may be recognized as amplified traits from the survivor's pre-injury self or as fundamental changes in an individual's propensities. Specific areas of personality change are impulsivity, irritability, and affective lability. These problem areas may be observed as speaking without thinking, poor judgment and reasoning, disproportionate responses, and unstable exaggerated displays of emotion, respectively. Observations are considered with respect to the pre-injured self (McAllister, 2008). Neurobehavioral symptoms are of larger concern for survivors' long-term quality of life and social and professional engagement (King & Kirwilliam, 2011; McAllister, 2008).

TBI is too often discussed as a single event, while recent literature substantiates TBI as a chronic condition (Corrigan & Hammond, 2013; Johnson, Stewart & Smith, 2011; Masel &

DeWitt, 2010; Vaishnavi, Rao, & Fann, 2009). The World Health Organization (WHO) defines chronic condition as permanent, caused by irreversible, pathological alterations, and requiring long-term supervision or care (Masel & DeWitt, 2013). A single TBI can induce permanent, neuropathologic changes similar to those observed in neurodegenerative diseases, validating TBI as a chronic condition (Corrigan & Hammond, 2013). Due to the permanence of physiological changes post-injury, survivors experience symptoms that potentially change their sense of self, normalcy, and ability for the rest of their lives (McAllister, 2008).

The experience of caring for a TBI survivor parallels that of caring for other neurogenic chronic conditions in regard to psychological health, effects on relationships, and emotional endurance (Holmes & Deb, 2003). Positive correlations are found between caring for a partner with a chronic condition and caregivers' psychological distress (Holmes & Deb, 2003; Kreutzer, Gervasio & Camplair, 1993; Vitaliano, Zhang & Scanlan, 2003). Neurobehavioral problems, cognitive dysfunction, aggressiveness, and uninhibited social behavior are significantly associated with psychological distress. Moreover, the psychological distress resulting from the caregiver burden is more closely related to duration of neurobehavioral symptoms than to severity of injury (Blaise & Boisvert, 2005). Additionally, while long-term romantic relationships inevitably experience flux in partner roles throughout years together, couples enduring chronic conditions bear permanence in role change. Non-injured partners take on the role of caregivers in addition to assuming other functional roles, affecting mutuality in relationships. As TBI survivors experience fundamental personality changes, caregivers are suddenly in a relationship with a seemingly new person (Kreutzer, et. al., 2007). Caregivers' emotional endurance is often taxed by increased levels of stress, depression and anxiety, decreased social interaction, and isolation (Blaise & Boisvert, 2005). Mild TBIs that subject

survivors and caregivers to chronic symptoms warrant academic attention to the potential deterioration of social support.

Common changes experienced in romantic relationships pre- to post-TBI fall within themes of ambiguous loss, identity reformation, tenuous stability, and non-omnes moriar (not all of us is dead). Ambiguous loss suggests grieving the loss of someone who is physically still alive, but whose essence has changed as a result of his or her injury. The survivor and caregiving partner may experience grief over the loss of self or loss of partner, respectively, but both individuals may also grieve the loss of *us* – the previous relationship (Godwin, Chappell & Kreutzer, 2014). Perceived identity change typically indicates a negative change from pre- to post-injury self. Perceived identity change positively correlates with depression and grief, and negatively correlates with self-esteem and self-awareness. Such co-morbidities perpetuate the sense of ambiguous loss for the survivor and relationship that are still physically present (Carroll & Coetzer, 2011).

Changes in self are the more complex consequences of TBI (Ownsworth, 2014). Identity reformation is a common experience as part of post-traumatic growth and the process of recovering and moving on after a TBI (Godwin, et. al., 2014; Powell, Gilson & Collin, 2012). Finding a new sense of self or purpose is a primary indicator of the survivor's physical and psychological recovery (Powell, et. al., 2012). The survivor's identity reformation experience also correlates with changes in family identity and determines chance of meaningful growth and recovery for the family unit as well. Survivors and their families will need to recover together post-TBI (Ownsworth, 2014).

During the TBI rehabilitation process, tenuous stability is experienced in typically stable aspects of romantic relationships. In a healthy, mutual, committed relationship, couples should feel emotional, commitment, and connective stability (Godwin, et. al., 2014). However, following a TBI, non-injured partners may lose their major source of emotional support and companionship, may now be tasked with all parenting responsibility, and may have lost intimacy and empathetic communication with their partner. Non-injured partners' role as caregiver may take on a parent-child dynamic, also incompatible with roles and expectations of a romantic partner (Blaise & Boisvert, 2005).

Some couples are able to work through the uncertainty, changes, and challenges to discover not all of who they used to be are gone – *non-omnes moriar* (Godwin, et. al., 2014). Shortly after the injury, and throughout the period of intense medical attention and rehabilitation efforts, partners may struggle to see each other external to the injury, caregiving responsibilities, therapies, doctor appointments, or legal cases. However, many couples eventually find that despite significant changes, not all parts of their partner and relationship are lost (Blaise & Boisvert, 2005). With awareness of the feat that lays ahead, conscious rehabilitation, and a strong support system, couples can successfully cope with, adjust to, and overcome the effects of TBI on their romantic relationships.

Chapter 3: Methodology

Qualitative methods are substantiated in research that seeks to investigate and understand complex experiences or phenomena from the perspective of those being studied (Curry, Nembhard & Bradley, 2009). The often complex, ambiguous experience of life after brain injury warrants a less restrictive means of inquiry. Methods such as phenomenology, in the case of this study, are most often mixed with a quantitative methodology for the purposes of: *grounding* quantitative results in context, *framing* the issue prior to interviewing, *orienting* subjects to the topic, *confirming* results of different methods, or *layering* analysis for a better reflection of data. Mixed methods research (MMR) is increasing in popularity due to its inclusive representation of subject matter. An abundance of MMR is conducted in the health science field, a trend likely associated with a greater interest in understanding personal experiences to inform clinical practices (Mayoh & Onwuegbuzie 2014). By utilizing a mixed methods approach, the breadth of data provided by quantitative methods in this study will *frame* the depth provided by qualitative methods.

This is a preliminary study investigating changes in romantic relationships post-brain injury. Data were collected during Summer-Fall 2015 after the researcher received approval from the James Madison University Institutional Review Board – (protocol number 16-0001).

Research Questions

1. What specific changes are experienced within romantic relationships following a mild TBI?
2. How does one's work and leisure change after a mild TBI?
3. What are successful strategies for coping with and adjusting to relational changes resulting from a mild TBI?

Design

This study implemented a convergent parallel design to quantitatively confirm the environment of romantic relationships after brain injury, while qualitatively pursuing an understanding of couples' reactions to that environment. Two phases of data collection were implemented: 1) A questionnaire to assess relationship satisfaction, role changes and dynamics pre- and post- injury, and 2) One-on-one interviews with two couples to discuss successful strategies that they have employed to cope with and adjust to those changes. A mixed methodology allowed for a greater sample size to inform the results on common themes of change, while also acknowledging the value of more elaborate responses gained from face-to-face interviews.

Questionnaire: Descriptive, quantitative data was obtained through a questionnaire consisting of 99 items adapted from the Couples Satisfaction Index (Funk & Rogge, 2007) and the Mayo Portland Adaptability Inventory-4 (Malec, 2005).

The Couples Satisfaction Index (CSI) is a 32-item questionnaire measuring one's satisfaction in their romantic relationship (Appendix A). The CSI appeared twice in the questionnaire, in reference to the participants' relationship before (1) and after (2) the mTBI occurred. Items assess various components of a healthy, supportive romantic relationship on a scale of 0-5. The index utilizes Likert scale ranking, yielding interval data. A cumulative, continuous score is reported for each iteration of the instrument. The CSI was found to be a valid and reliable measure of relationship satisfaction in previous research as indicated by a Cronbach alpha level of 0.98 (Funk & Rogge, 2007, page 579).

The Mayo-Portland Adaptability Inventory-4 (MPAI-4) is a 30-item questionnaire consisting of subscales for ability, adjustment, and participation in regards to activities of daily living, work, and leisure (Appendix A). The MPAI-4 uses interval rankings to assess a subject's involvement in these three areas. Subscales are scored individually, summed to create a full scale score. The full scale score and individual subtest scores are analyzed in comparison to normative samples. The MPAI-4 has previously shown to be a valid and reliable measure of ability, adjustment, and participation with a Cronbach alpha level of 0.79 (Malec, 2008, page 58).

Interview: Phenomenological case study data were obtained through a structured interview following a modified version of the Iowa Collateral Head Injury Interview script (Varney, 1989).

The Iowa Collateral Head Injury Interview is comprised of questions directed at 21 different symptoms often experienced post-TBI (Appendix A). The interview lays out specific follow-up questions, which were modified to prompt interviewees to discuss strategies they employ to address the symptom in question. The original interview was written for an interview with a partner, so the wording was also adapted for the interview with the survivor. Additionally, the interview is typically scored by assigning numerical values (0-2) to denote change post-injury. For the purpose of this study, interviews were recorded and transcribed to be qualitatively analyzed. This instrument has previously presented valid and reliable with a Cronbach's alpha of 0.94 (Varney, 1989).

Participants and Procedure

Participants in this study identified as either having suffered a mild TBI or being a romantic partner of an individual who has suffered a mild TBI. The relationship must have been

intact prior to and immediately after injury. Convenience and purposeful sampling were used to identify potential participants through rehabilitation centers in Richmond, Virginia, and support groups throughout Virginia.

Questionnaire: Signs were posted at each recruitment site, explaining the study and inviting TBI survivors and caregivers to participate. Additionally, the primary researcher was present in neurorehabilitation clinics and support group meetings to invite patients or attendees to participate. Participation was strictly voluntary and in no way affected patients' medical care. Questionnaires were administered on-site and collected by the primary researcher. Questionnaires were completed confidentially. Responses were not associated with personal information of specific participants.

Interview: Partnering physicians and professional consultants identified two experienced couples as potential participants for the case study interview phase. Participants consisted of two married, heterosexual couples. One couple was affected by the husband's mTBI, and the other couple was affected by the wife's mTBI. These couples were invited to participate on a strictly voluntary basis, participation in no way affecting their care at the practice. Romantic partners were interviewed individually to maintain confidentiality and extract honest perspectives. Interviews were conducted by the primary researcher in private rooms, and recorded using a tape recorder. The primary researcher also transcribed each interview.

Data Analysis

Following data collection, quantitative data on relationship satisfaction and role change characteristics were analyzed via SPSS. Specifically, paired t-tests were used to identify significant changes from pre- to post- injury. Regression analyses were run to investigate a

relationship between symptom severity and change in relationship satisfaction. With a phenomenological approach, interview transcriptions were analyzed using the qualitative analysis software *NVivo* 11[®] for emergent themes of coping strategies and experiences. Consensus coding contributed to the development of themes.

Chapter 4: Results

Phase One: Questionnaire Results

All participants identified being in a relationship affected by a mild TBI, as diagnosed by a physician. Survivors constituted 53.7% of the sample; caregivers constituted 46.3%. Of the sample, 14.6% of individuals were no longer in the romantic relationship from the time of injury; 85.4% are still with their partner. Demographics were further analyzed to compare perspectives on romantic relationships post-mTBI (Table 1).

Table 1. *Sample Demographics*

	Frequency (n)	Percent of total (%)
Total	41	100
Survivor	22	53.7
Survivor-Male	11	26.8
Survivor-Female	11	26.8
Caregiver	19	46.3
Caregiver-Male	5	12.2
Caregiver-Female	14	34.1
Male	16	39
Female	25	61
Still together	35	85.4
No longer in relationship	6	14.6

Couples having experienced a TBI to one partner reported a significantly lower relationship satisfaction score post-injury than pre-injury ($n=41$; $p=0.000$). Out of a possible 161, the average pre-injury relationship satisfaction score was 136.24, compared to the average post-injury relationship satisfaction score of 99.68 (Table 2). The CSI was also analyzed by individual item (Table B3). A significant decrease in satisfaction was observed on 30 out of 32 individual items. Items 10 ($p=0.689$) and 15 ($p=0.150$) did not reflect significant change. Item 10 asked participants to respond to “I sometimes wonder if there is someone else out there for me”

on a scale of “Not at all true” to “Completely true”. Item 15 asked participants to respond to “I have had second thoughts about this relationship recently” on a scale of “Not at all true” to “Completely true”. The largest decreases in satisfaction were noted on the following items: (1) “degree of happiness, all things considered”, (4) “demonstration of affection”, and (17) “I really feel like part of a team with my partner”, as well as ranking how one feels about the relationship (items 26-32).

Table 2. *Couples Satisfaction Index (CSI) Scores – total*

	Total (n=41)
Pre-injury relationship satisfaction	136.24
Post-injury relationship satisfaction	99.68
Significance (p-value)	0.000*

Survivor and caregiver relationship satisfaction were compared to assess different experiences between the two roles. Due to the small cell size, non-parametric Mann-Whitney U tests were run to compare survivor (n=22) and caregiver (n=19) relationship satisfaction scores for pre-injury and post-injury (Table 4). Little difference was found between survivor ($x=135.05$) and caregiver ($x=137.63$) pre-injury reports ($p=.979$). However, although not statistically significant, caregivers ($x=92.21$) reported an average post-injury relationship satisfaction lower than survivors (106.14) ($p=.234$). Caregivers (45.42) also reported a greater average decrease in satisfaction, pre-injury to post-injury, than survivors (28.91) ($p=.102$). Individual CSI items were analyzed for variation between survivor and caregiver, producing no significant variation on pre-injury items. Significant variance on post-injury was observed between survivors and caregivers on items 20 and 26 (Table B5). When asked “How well does your partner meet your needs?” in reference to the relationship post-injury, caregivers rated an average 2.11 out of 5, significantly

lower than survivors' 3.41 out of 5 ($p=.004$). When asked to rank their romantic relationship post-injury on a scale of 0-5 from boring to interesting, caregivers rated an average 2.42 out of 5, significantly lower than survivors' 3.41 out of 5 ($p=.044$). Caregivers reported lower satisfaction than survivors on several other post-injury items, with p-values approaching significance. Items approaching significance included: (1) degree of happiness, all things considered ($p=.089$), (2) agreement on amount of time spent together ($p=.076$), (4) "demonstrations of affection" ($p=.079$), (16) "for me, my partner is the perfect romantic partner" ($p=.081$), and (24) "do you enjoy your partner's company?" ($p=.083$).

Table 4. *Couples Satisfaction Index (CSI) Scores – Survivor vs. Caregiver*

	Survivor (n=22)	Caregiver (n=19)	Sig. (p-value)
Pre-injury relationship satisfaction	135.05	137.63	0.979
Post-injury relationship satisfaction	106.14	92.21	0.234
Change in relationship satisfaction (pre-post)	28.91	45.42	0.102

Survivor and caregiver responses were also assessed by gender, comparing relationship satisfaction across four categories: survivor-male (SM), survivor-female (SF), caregiver-male (CM), and caregiver-female (CF). Dividing the sample in this way created small cell sizes; non-parametric tests were performed (Table 6). Kruskal Wallis tests reflected an increase in variance between groups from pre-injury ($p=.896$) to post-injury ($p=.151$), although not statistically significant at the .05 level. Pre-injury CSI scores showed little variance between groups' relationship satisfaction: SM=131.73, SF=138.36, CM=138.80, CF=137.21. Post-injury CSI scores indicated a decrease in relationship satisfaction in all groups: SM=98.55, SF=113.73, CM=114.80, CF=84.14 ($p=.151$). Average change in satisfaction was greater for caregiver-

females ($x=53.07$) and survivor-males ($x=33.18$) than caregiver-males ($x=24.00$) and survivor-females ($x=24.64$).

Table 6. *Couples Satisfaction Index (CSI) scores – Caregiver vs. Survivor, Male vs. Female*

	Survivor-Male (n=11)	Survivor-Female (n=11)	Caregiver-Male (n=5)	Caregiver-Female (n=14)	Sig. (p-value)
Pre-injury relationship satisfaction	131.73	138.36	138.80	137.21	0.896
Post-injury relationship satisfaction	98.55	113.73	114.80	84.14	0.151
Change in relationship satisfaction (pre-post)	33.18	24.64	24.00	53.07	0.102

Of all the relationships assessed, 4.9% reported symptom severity resulting in mild limitations as a result of mTBI, 7.3% reported moderate limitations, 46.3% reported moderate-severe limitations, and 41.5% reported severe limitations (Table 7). Although not statistically significant, caregivers reported higher means for symptom severity in their partner than survivors did in themselves (Table 8). However, symptom severity was not statistically significant in regression analyses for the prediction of change in relationship satisfaction.

Table 7. *Sample Demographics of Symptom Severity*

	Frequency (n)	Percent (%)
Good outcome (MPAI <30)	0	0
Mild limitations (MPAI 30-40)	2	4.9
Moderate limitations (MPAI 41-50)	3	7.3
Moderate-severe limitations (MPAI 51-60)	19	46.3
Severe limitations (MPAI >60)	17	41.5

Table 8. *Symptom Severity – Survivor vs. Caregiver*

	Survivor (n=22)	Caregiver (n=19)	Significance (p-value)
MPAI total	57	59	0.513
MPAI Ability Subscale	57	59	0.906
MPAI Adjustment Subscale	58	60	0.301
MPAI Participation Subscale	55	58	0.301

Phase Two: Interview Results

Four participants, two survivors and two caregivers, reported on symptom experience of the two survivors. Survivors and caregivers agreed on the presence of a majority of the symptoms discussed. All four participants reported survivors' difficulties with memory, communication, insight and empathy, motivation, mental flexibility, planning and anticipation, decision making, and physical intimacy. The two survivors referenced their tendencies toward a

flat or neutral affect and difficulty learning from experience. However, neither caregiver acknowledged the presence of these two symptoms.

Discussion of couples' mTBI experience as a result of individual symptoms yielded five salient themes. Participants referenced changes in self (of the survivor), effects of the brain injury on the romantic relationship, strategies they have implemented, advice for future couples enduring the brain injury experience, and reaction to resources available on the relationship component of rehabilitation (Appendix C). All participants contributed to the development of each theme.

Changes in self (survivor). Participants referenced a previous identity or previous self to which they now compare themselves or their partners. Survivors shared the sentiment of "I don't know who I am anymore." One claimed, "I live in someone else's world, someone else's body," and another stated, "I just exist." Comparisons were made to personality, productivity levels, abilities, and contribution to relationship. A survivor claimed, "I've become reclusive, introverted, flat." Another survivor described the change as feeling

"like a duck swimming in the water. Underneath, legs are moving 100 miles per hour, but on top, people only see the duck just floating along calmly. That's what life is for me now, and even my husband doesn't see how much harder I have to work just to live."

Changes in ability and stamina affect one's sense of self. One survivor remarked, "I was always energetic. I never said no. I was accomplished. I always had so many balls in the air. I could never imagine that life now." These individual changes affect the kind of partner survivors are post-injury. One survivor remembers the partner she used to be and stated, "I used to know my husband really well; I always knew what he was thinking and what he needed. I could

anticipate his feelings, needs and desires,” but admitted, “I’m not on the ball like I used to be.” She clarified by saying, “I spend my entire day concentrating so hard on making sure I get through the next minute that those things are not in my brain.”

Effect on relationship. Objective symptoms weigh on interpersonal interactions and romantic connection. Frustration was a common experience recognized by both caregivers and both survivors: “We don’t have a romantic relationship anymore. That was taken from me the day of my accident. That was the worst thing I lost,” one survivor stated. Another survivor described the relationship as being “even before [the injury], like 50-50. Now it is 90-10... I don’t hold up my end anymore.” Similarly, a caregiver expressed, “I don’t get to take time off. I have to be ‘on’ all the time.”

All participants referenced a change in relationship dynamic into superior-inferior roles. One survivor observed, “we used to be husband and wife, equal partners. Now I’m like her kid.” A caregiver stated, “I have to make all the decisions...it’s like a parent-child, doctor-patient relationship instead of an equal partnership.” Another caregiver confirmed, “it’s definitely not romantic having to be like a parent explaining to a child how things work or why we’re doing it this way.” Both caregivers made claims of isolation, and gave examples like: “If I ever want to go out to dinner or have a date night, that would be something I’d have to plan and drag him to,” and “I want someone to play with. I don’t have a buddy anymore.”

Fatigue influences the efficacy of survivors as romantic partners. A survivor described, “my thoughts in my mind take so much energy that I really do not have the energy to incorporate another person into that moment.” Another survivor stressed the ambiguity of the whole experience:

“After the injury you’re dealing with so much: the pain, rehabilitation, appointments, medications, tests, buying a new car, fighting with insurance companies. I don’t know what comes first, the chicken or the egg. Is it the injury or all the stuff that comes with it? All of a sudden it’s not the same and you don’t know when it stopped being the same.”

Physical intimacy also suffers due to physical and psychological reasons, further compromising romantic aspects of the relationship. A survivor described, “I have vertigo from the brain injury, which takes the spontaneity out of everything.” A caregiver elaborated, “sex has become so careful and calculated. Avoiding certain positions takes away the naturalness of sex...it puts a divide between us.” One survivor lamented, “there are still kisses, hugs and cuddling, but...a relationship with sex, that’s over. It hasn’t happened since the accident. I don’t like to think about it. It’s too big, too painful and makes me feel inadequate.”

Strategies. Participants discussed strategies broadly in terms of attitude and perspective on the experience, while also offering specific strategies used to address particular challenges within their relationship. In general, “we pick each other up. I pick up the slack. I remind myself she is doing the best she can. I accept where she’s at and choose to focus on her 40 other good qualities,” said a caregiver. A survivor explained, “we tell each other, ‘It’s going to be okay in the end. We’re going to get there,’ and that we love each other, and that this is the definition of... ‘for better or for worse.’” Determination, positivity, and teamwork are crucial components to these couples’ successes.

Survivors referenced written reminders and adjusted expectations as strategies to address role fulfillment, such as “everything is on the calendar,” said one survivor. Another survivor explained,

“I write everything down! Every morning I have to make a list of everything to do that day, and I organize it by priority, and in the evening if anything hasn’t gotten done I start a new list for the next day.”

Survivors and caregivers also learn to incorporate acceptance of the brain injury experience into their expectations of role fulfillment: “I’ve learned what I can cope with. We pay someone to clean the house now. We eat out more than we used to. I don’t change the sheets every 3-4 days; I change them every 7-8 days,” admitted a survivor.

Brain injuries challenge communication dynamics, which over time determine relationship dynamics, as explained by a caregiver:

“Our communication strategy is to mirror what the other person is saying to check for understanding and to validate and empathize with their experience. He’ll say I’m being condescending or bossing him around, and I’ll have to mirror or repeat that back so he knows I understand his experience.”

Both survivors referenced difficulty accurately articulating what they mean to say: “I have to apologize a lot [for things I say], but he is very good about giving me a second chance to say it right. He is very understanding and patient,” gratified a survivor. Communicating with patience and without a negative attitude was stressed from all participants as an important strategy for maintaining respectful relationship dynamics.

The purposeful romantic components of the relationship are easily forgone during the stress of recovery. However, conscious attention of this tendency can help ensure the romance is not completely lost: “I try not to wear the doctor hat all the time. Sometimes I just need to be her husband,” said a caregiver. Participants reported separating the multiple roles a caregiver serves

ensures each role is effectively cast. One survivor said, “we schedule a movie night or game night regularly.” Another caregiver reported, “we have a list of restaurants and fun activities written on index cards, and he can pick one out on the night of the week we’ve set aside for that.” Lessening the stress of initiation, decision making, and spontaneity can ease the romance back into the relationship.

Discontent with resources. Participants expressed frustration with the lack of resources and lack of professional attention to the emotional and interpersonal effects their own or their partner’s mTBI has on the romantic relationship. One survivor shared,

“I don’t think they address it at all. Even when we were going through the lawsuit, [my husband] and I both explained how badly this affected our personal selves and personal relationship, and they just blew that off. I think it makes them uncomfortable, but it’s huge.”

Similarly, another survivor claimed, “nobody deals with the emotional aspect.” A caregiver quipped, “We’re not even part of the equation, but we’re doing everything.”

Both caregivers stressed a lack of information in addition to lack of attention, as evidenced by the following quote:

“Nothing has been addressed in terms of our relationship. I would have loved someone to explain things to me, like why my wife is different, why she does certain things. I’d like to know if this is normal or common after a brain injury.”

Comparatively, another caregiver shared, “you get these generic sections in a book saying, ‘you will experience these things.’” Another caregiver lamented, “education is such a huge missing

part of treatment. Caretakers already feel totally burdened and isolated, and they get nothing from doctors.”

Advice. Sentiments of advice and encouragement arose from participants’ reflections on their relationships: “You have to have three keys to make it work. You still have to love each other; one of you has to be an excellent communicator; there has to be patience,” said one survivor. Both caregivers suggested a change in perspective: “Forget about each week, each month, each year. It’s about surviving each day and each interaction between you,” offered one caregiver. Another caregiver explained, “she isn’t doing it to piss you off; it’s the brain injury.” Brain injury recovery is a long process, not a short fix, as stressed by one survivor:

“Don’t make any judgments or any decisions until you’re way down the road, because so much changes, so many times, so drastically. Don’t quit. It does get better. You find the new dance, the new rhythm between you. It’s a new relationship but you find your way.”

A caregiver concluded, “You can mourn the past, but you can’t live in it.” This latter quote essentially summarizes the new normal that the couples interviewed for the current study experienced post-injury and the emotional, mental, and physical adjustments such an experience brings.

Chapter 5: Discussion

The current study aimed to identify changes in romantic relationships after one partner suffered a mild TBI, and to present advice from affected couples to future affected couples and health care providers. A major contribution of this study is the opportunity for survivors and caregiving partners to have their unique voices represented in the literature. Additionally, as isolation was a theme identified in the experience of a romantic relationship post-TBI, this study may serve as a resource and cultivate support for future couples affected by brain injury. The current data confirmed the significant decrease in satisfaction and the necessity of providing adoptable strategies.

Quantitative analysis confirmed a significant decrease in relationship satisfaction after brain injury. The majority of participants reported symptom severity resulting in moderate to severe limitations. Participants experienced symptoms affecting their physical abilities (i.e. sensory, motor, and cognitive abilities), emotional adjustment (i.e. mood, fatigue, interpersonal interactions), and engagement and participation (i.e. social contacts, employment, transportation, money management) with similar moderate-severe limitations. However, symptom severity was not a predicting factor of relationship satisfaction (Blaise & Boisvert, 2005).

Questionnaire and interview data revealed prominent sources of relationship frustration, such as changes in survivor sense of self, role fulfillment, communication between partners, and partner dynamics. Changes in survivors' self concept determined the saliency of all subsequent themes. One's self concept is constructed in relation to others and by the roles he serves (Ponsford, Kelly & Couchman, 2014). The research substantiates cognition, behavioral, and personality changes as a result of brain injury (King & Kirwilliam, 2011; McAllister, 2008).

Nevertheless, the present study found such symptoms determine survivors' ability to fulfill roles previously performed; challenge effective communication about daily matters, large decisions, and personal feelings; and compromise equal partner dynamics.

Frustration ensues between both survivors and caregivers as a result of loss of the *old* survivor, increased burden on the caregiving partner, lack of interpersonal connection, and lack of intimacy. Survivors lamented their inability to maintain certain roles – in the home, as providers, and as romantic partners. Increased awareness of symptoms is unique to milder injuries (Joseph, et al., 2015). Survivors were able to reflect and identify deficits, but still struggled to counter them on a regular basis with their partner. Variance between survivor and caregiver relationship satisfaction scores reflected greater cynicism from caregivers, supporting concern for deterioration of survivors' social support. Caregivers stressed the lack of resources available to them, and both caregivers and survivors stressed the lack of attention paid to survivors' roles as romantic partners.

While aggregate data suggested a grim outlook for relationship satisfaction post-TBI, a sense of partners' loyalty was evident in the analysis of questionnaire and interview results, confirming previous studies' findings (Godwin, et. al., 2014). Strategies and advice proposed by the experienced couples in the present study revealed positivity and hope, despite frustration and decreased relationship satisfaction. To successfully maneuver a romantic relationship after brain injury, it is important to accept the *new normal*, love and appreciate the other's effort, focus on short-term progress, and avoid becoming overwhelmed by the journey as a whole. Together, couples affected by brain injury should be willing to adjust their expectations of the survivor and the relationship, implement accommodations for symptoms to allow the survivor to recover as an individual and as a partner, communicate openly with patience and empathy – perhaps even

more often than before –, and consciously reintegrate important romantic elements to avoid losing them altogether.

Based on the aforementioned findings, several important implications warrant discussion. Social support is crucial to recovery, as evidenced by the couples in the current study. Rehabilitation efforts between survivors and clinicians are unlikely to effectively carry over into survivors' lives, if their home lives are not conducive to recovery. Survivors and caregivers both experience physical exhaustion and psychological distress that challenge the efficacy with which they support and serve each other (Blaise & Boisvert, 2005). To ensure each partner is able to best perform his or her role in the recovery process, professionals should acknowledge the health of the romantic relationship alongside rehabilitation of other objective mTBI symptoms.

Limitations of the current study preclude generalizability of the findings. As a local pilot study, a convenience sample was recruited from two specific neurorehabilitation centers and one brain injury support group. The sample was not randomized, and individuals generally frequent these establishments because they are experiencing more problematic symptoms than average mTBI cases. Additionally, pre- and post-TBI relationship satisfaction scores were reported post-TBI. Participants may be nostalgic regarding their pre-TBI relationship and could unintentionally idealize the relationship in comparison. Brain injury survivors also characteristically experience memory difficulties, potentially challenging perception and recall of the pre-TBI relationship.

Future studies may seek to expand similar inquiries across a greater sample size, and try to illicit a greater variety of strategy suggestions. Upon reflection of differences between the male and female survivors, future research may also be interested in investigating the influence of gender roles on the brain injury experience. Furthermore, given the significant impact on

romantic relationships, expanding upon this pilot study to investigate the impact on a nuclear family unit is recommended.

The findings of the present study offer some advice and strategies for couples affected by mTBI but, more importantly, emphasize the need for individualized attention to survivors' romantic relationships. Understanding the complex, ambiguous experience of a romantic relationship affected by brain injury is essential for professionals to comprehensively treat and for couples to comprehensively recover. Tailoring rehabilitation or offering services to address emotional and interpersonal symptoms will improve the quality of life and success of treatment for TBI survivors and caregivers. In conclusion, the noted effects of mTBI on romantic relationships should be considered symptoms of the brain injury, and therefore addressed through conscious relationship rehabilitation.

References

- Blaise, M., & Boisvert, J. (2005). Psychological and marital adjustment in couples following a traumatic brain injury (TBI): A critical review. *Brain Injury, 19*(14), 1223-1235.
- Carroll, E., & Coetzer, R. (2011). Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological Rehabilitation: An International Journal, 21*(3), 289-305.
- Corrigan, J., & Hammond, F. (2013). Traumatic brain injury as a chronic health condition. *Archives of Physical Medicine & Rehabilitation, 94*(6), 1199-1201.
- Curry, L. A., Nembhard, I. M., & Bradley, E. H. (2009). Qualitative and mixed methods provide unique contributions to outcomes research. *Circulation, 119*(10), 1442-1452.
- Esselman, P., & Uomoto, J. (1995). Classification of the spectrum of mild traumatic brain injury. *Brain Injury, 9*(4), 417-424.
- Funk, J. L., & Rogge, R. D. (2007). Testing the ruler with item response theory: Increasing precision of measurement for relationship satisfaction with the couples satisfaction index. *Journal of Family Psychology, 21*(4), 572-583. Retrieved from <http://www.courses.rochester.edu/surveys/funk/Funk%20&%20Rogge%202007.pdf>
- Godwin, E., Chappell, B., & Kreutzer, J. (2014). Relationships after TBI: A grounded research study. *Brain Injury, 28*(4), 398-413.
- Holmes, A., & Deb, P. (2003). The effect of chronic illness on the psychological health of family members. *The Journal of Mental Health Policy and Economics, 6*, 13-22.
- Johnson V., Stewart W., & Smith D. (2011). Widespread tau and amyloid-beta pathology many years after a single traumatic brain injury in humans. *Brain Pathology, 22*, 142-149.
- Joseph, B., Pandit, V., Aziz, H., Kulvatunyou, N., Zangbar, B., Green, D. J., Haider, A., Tang,

- A., O’Keeffe, T., Gries, L., Friese, R. S., & Rhee, P. (2015) Mild traumatic brain injury defined by Glasgow Coma Scale: Is it really mild?, *Brain Injury*, 29(1), 11-16. doi: 10.3109/02699052.2014.945959
- Khan, F., Baguley, I., & Cameron, I. (2003). Rehabilitation after traumatic brain injury. *Medical Journal of Australia*, 178, 290-295.
- King, N., & Kirwilliam, S. (2011). Permanent post-concussion symptoms after mild head injury. *Brain Injury*, 25(5), 462-470.
- Kreutzer, J., Gervasio, A., & Camplair, P. (1994). Primary caregivers’ psychological status and family functioning after traumatic brain injury. *Brain Injury*, 8(3), 197-210.
- Kreutzer, J. S., Marwitz, J. H., Hsu, N., Williams, K., & Riddick, A. (2007). Marital stability after brain injury: An investigation and analysis. *Neurorehabilitation*, 22(1), 53-59.
- Malec, J. (2005). The Mayo-Portland Adaptability Inventory. *The Center for Outcome Measurement in Brain Injury*. Retrieved from <http://www.tbims.org/combi/mpai>
- Malec, J. (2008). Manual for the Mayo-Portland adaptability inventory (MPAI-4) for adults, children and adolescents. *The Center for Outcome Measurement in Brain Injury*. Retrieved from <http://www.tbims.org/combi/mpai/manual>
- Masel, B., & DeWitt, D. (2010). Traumatic brain injury: A disease process, not an event. *Journal of Neurotrauma*, 27(8), 1529-1540.
- Mayoh, J., & Onwuegbuzie, A. J. (2014). Surveying the landscape of mixed methods phenomenological research. *International Journal of Multiple Research Approaches*, 8(1), 2-14.
- McAllister, T. (2008). Neurobehavioral sequelae of traumatic brain injury: Evaluation and management. *World Psychiatry*, 7(1), 3–10.

- Owensworth, T. (2014). *Self-identity after brain injury*. New York, NY: Psychology Press.
- Ponsford, J., Kelly, A., & Couchman, G. (2014). Self-concept and self-esteem after acquired brain injury: A control group comparison. *Brain Injury*, 28(2), 146-154.
- Powell, T., Gilson, R., & Collin, C. (2012). TBI 13 years on: Factors associated with post-traumatic growth. *Disability & Rehabilitation*, 34(17), 1461-1467.
- Varney, N. (1989). Iowa collateral head injury interview. *Neuropsychology*, 5, 223-225.
- Vitaliano, P., Zhang, J., & Scanlan, J. (2003) Is caregiving hazardous to one's physical health? A metaanalysis. *Psychological Bulletin*. 129(6), 946-972.

Appendix A

An Assessment of the Impact of Mild Traumatic Brain Injury (mTBI) on Romantic Relationships

1. For the purpose of this study, do you identify as: (circle a or b)
 - a. Having sustained a TBI, personally
 - b. A romantic partner of an individual who has sustained a TBI
2. Do you identify as MALE or FEMALE? Please circle one.
3. When did your romantic relationship, at the time of injury, begin (mm/yyyy)?

4. Are you currently in the same romantic relationship as at the time of injury? Circle one: YES or NO
5. When did your (or your partner's) TBI occur (mm/yyyy)? _____

For the following items, please answer in regards to your relationship **PRIOR to the injury**.

1. Please indicate the degree of happiness, all things considered, of your relationship **prior to the injury**:

Extremely Unhappy	Fairly unhappy	A little unhappy	Happy	Very Happy	Extremely Happy	Perfect
0	1	2	3	4	5	6

Most people have disagreements in their relationships. Please indicate below the proximate extent of agreement or disagreement between you and your partner **prior to the injury** for each item:

	Always disagree	Almost always disagree	Frequently disagree	Occasionally disagree	Almost always agree	Always agree
2. Amount of time spent together	0	1	2	3	4	5
3. Making major decisions	0	1	2	3	4	5
4. Demonstration of affection	0	1	2	3	4	5

	Never	Rarely	Occasionally	More often than not	Most of the time	All of the time
5. In general, how often do you think things between you and your partner are going well?	0	1	2	3	4	5
6. How often do you wish you had not gotten into this relationship?	0	1	2	3	4	5

For the following items, please answer in regards to your relationship **PRIOR to the injury**.

	Not at all true	A little true	Somewhat true	Mostly true	Almost completely true	Completely true
7. I feel a strong connection with my partner.	0	1	2	3	4	5
8. If I had my life to live over, I would marry/live with/date the same person.	0	1	2	3	4	5
9. Our relationship is strong.	0	1	2	3	4	5
10. I sometimes wonder if there is someone else out there for me.	0	1	2	3	4	5
11. My relationship with my partner makes me happy.	0	1	2	3	4	5
12. I have a warm and comfortable relationship with my partner.	0	1	2	3	4	5
13. I can't imagine ending my relationship with my partner.	0	1	2	3	4	5
14. I feel that I can confide in my partner about virtually anything.	0	1	2	3	4	5
15. I have had second thoughts about this relationship recently.	0	1	2	3	4	5
16. For me, my partner is the perfect romantic partner.	0	1	2	3	4	5
17. I really feel like part of a team with my partner.	0	1	2	3	4	5
18. I cannot imagine another person making me as happy as my partner does.	0	1	2	3	4	5

For the following items, please answer in regards to your relationship **PRIOR to the injury**.

	Not at all	A little	Somewhat	Mostly	Almost Completely	Completely
19. How rewarding is your relationship with your partner?	0	1	2	3	4	5
20. How well does your partner meet your needs?	0	1	2	3	4	5
21. To what extent has your relationship met your original expectations?	0	1	2	3	4	5
22. In general, how satisfied are you with your relationship?	0	1	2	3	4	5

	Worse than all others (extremely bad)					Better than all others (extremely good)
23. How good is your relationship compared to most?	0	1	2	3	4	5

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
24. Do you enjoy your partner's company?	0	1	2	3	4	5
25. How often do you and your partner have fun together?	0	1	2	3	4	5

Mark the box that best describes *how you felt about your relationship*. Consider “in between” boxes too. Base your responses on your first impressions and immediate feelings about the item.

26. INTERESTING							BORING
27. BAD							GOOD
28. FULL							EMPTY
29. LONELY							FRIENDLY
30. STURDY							FRAGILE
31. DISCOURAGING							HOPEFUL
32. ENJOYABLE							MISERABLE

For the following items, please answer in regards to **AFTER the injury**.

Below each item, circle the number that best describes the level at which you (or your partner) experiences problems. Mark the greatest level of problem that is appropriate. Problems that interfere rarely with daily or valued activities, that is, less than 5% of the time, should be considered not to interfere.

	None	Mild problem: but does not interfere with activities; may use assistive device or medication	Mild problem: interferes with activities 5- 24% of the time	Moderate problem: interferes with activities 25- 75% of the time	Severe problem: interferes with activities more than 75% of the time
1. Mobility – problems walking or moving; balance problems that interfere with moving about	0	1	2	3	4
2. Use of hands – impaired strength or coordinator in one or both hands	0	1	2	3	4
3. Vision – problems seeing; double vision, blurry vision, eye/brain/nerve injury that interfere with seeing	0	1	2	3	4
4. Audition – problems hearing; ringing in ears	0	1	2	3	4
5. Dizziness – feeling unsteady, dizzy, light headed	0	1	2	3	4
6. Motor speech – abnormal clearness or rate of speech; stuttering	0	1	2	3	4
7A. Verbal communication – problems expressing or understanding language	0	1	2	3	4

For the following items, please answer in regards to **AFTER the injury**.

	None	Mild problem: but does not interfere with activities; may use assistive device or medication	Mild problem: interferes with activities 5- 24% of the time	Moderate problem: interferes with activities 25- 75% of the time	Severe problem: interferes with activities more than 75% of the time
7B. Nonverbal communication – restricted or unusual gestures or facial expression; talking too much or not enough; missing nonverbal cues from others	0	1	2	3	4
8. Attention and concentration – problems ignoring or distractions, shifting attention, keeping more than one thing in mind at a time	0	1	2	3	4
9. Memory – problems learning and recalling new information	0	1	2	3	4
10. Fund of Information – problems remembering information learned in school or on the job; difficulty remembering information about self or family from years ago	0	1	2	3	4
11. Novel problem-solving – problems thinking up solutions or picking the best solutions to new problems	0	1	2	3	4
12. Visuospatial abilities – problems drawing, assembling things, route-finding, being visually aware on both left/right sides	0	1	2	3	4

For the following items, please answer in regards to **AFTER the injury**.

	None	Mild problem: but does not interfere with activities; may use assistive device or medication	Mild problem: interferes with activities 5-24% of the time	Moderate problem: interferes with activities 25-75% of the time	Severe problem: interferes with activities more than 75% of the time
13. Anxiety – tense, nervous, fearful, phobias, nightmares, flashbacks of stressful events	0	1	2	3	4
14. Depression – sad, blue, hopeless, poor appetite, poor sleep, worry, self-criticism	0	1	2	3	4
15. Irritability, anger, aggression – verbal or physical expressions of anger	0	1	2	3	4
16. Pain and headache – verbal and nonverbal expressions of pain, activities limited by pain	0	1	2	3	4
17. Fatigue – feeling tired; lack of energy; tiring easily	0	1	2	3	4
18. Sensitivity to mild symptoms – focusing on thinking, physical or emotional problems attributed to brain injury; rate only how concern or worry about these symptoms affects current functioning	0	1	2	3	4
19. Inappropriate social interaction – acting childish, silly, rude behavior not fitting for time/place	0	1	2	3	4
20. Impaired self-awareness – lack of recognition of personal limitations and disabilities and how they interfere with everyday life	0	1	2	3	4

For the following items, please answer in regards to **AFTER the injury**. Use the scale below to rate the level at which the following items interfere with participation in life activities.

21. **Stress within the family/significant relationships** – “Family functioning” means cooperating to accomplish those tasks that need to be done to keep the household running.

Normal stress within family or other close network of relationships.	Mild stress that does not interfere with family functioning	Mild stress that interferes with family functioning 5-24% of the time	Moderate stress that interferes with family functioning 25-75% of the time	Severe stress that interferes with family functioning more than 75% of the time
0	1	2	3	4

22. **Initiation** – problems getting started on activities without prompting.

None	Mild problem that does not interfere with activities; may use assistive device	Mild problem that interferes with activities 5-24% of the time	Moderate problem that interferes with activities 25-75% of the time	Severe problem that interferes with activities more than 75% of the time
0	1	2	3	4

23. **Social contact** with friends, work associates, and other people (NOT family, partners or professionals)

Normal involvement with others	Mild difficulty in social situations but maintains normal involvement with others	Mildly limited involvement with others (75-95% of normal interaction for age)	Moderately limited involvement with others (25-74% of normal interaction for age)	No or rare involvement with others (less than 25% of normal interaction for age)
0	1	2	3	4

24. **Leisure and recreational activities** – participation in same activities as prior to injury

Normal participation in leisure activities for age	Mild difficulty in these activities but maintains normal participation	Mildly limited participation (75-95% of normal participation for age)	Moderately limited participation (25-74% of normal participation for age)	No or rare participation (less than 25% of normal participation for age)
0	1	2	3	4

25. **Self-care** – eating, dressing, bathing, hygiene

Independent completion of self-care activities	Mild difficulty, occasional omissions or mildly slowed completion of self-care; may use assistive device	Requires a little assistance or supervision from others (5-24% of the time) including frequent prompting	Requires moderate assistance or supervision from others (25-75% of the time)	Requires extensive assistance or supervision from others (more than 75% of the time)
0	1	2	3	4

26. **Residence** – responsibilities of independent living and homemaking (meal preparation, home repairs and maintenance, personal health maintenance beyond basic hygiene, medication management)

Independent; living without supervision or concern from others	Living without supervision but others have concerns about safety or managing responsibility	Requires a little assistance or supervision from others (5-24% of the time)	Requires moderate assistance or supervision from others (25-75% of the time)	Requires extensive assistance or supervision from others (more than 75% of the time)
0	1	2	3	4

27. **Transportation**

Independent in all modes of transportation including independent ability to operate motor vehicle	Independent in all modes of transportation but others may have concerns about safety	Requires a little assistance or supervision from others (5-24% of the time); cannot drive	Requires moderate assistance or supervision from others (25-75% of the time); cannot drive	Requires extensive assistance or supervision from others (more than 75% of the time); cannot drive
0	1	2	3	4

28A. **Paid employment** – “support” means special help from another person. Modifications to the physical environment that facilitate employment are not considered as support.

Full time (>30 hours/week) without support	Part time work (3-30 hours/week) without support	Full time or part time with support	Sheltered work	Unemployed; employed less than 3 hours/week
0	1	2	3	4

28B. **Other employment** – Involved in constructive, role appropriate activity other than paid employment. Circle one to indicate primary desired social role: Childrearing/caregiving, Homemaker (without children) Student, Volunteer, Retired (only if over age 60)

Full time (more than 30 hours/week) without support	Part time work (3-30 hours/week) without support	Full time or part time with support	Activities in a supervised environment	Inactive; involved in role-appropriate activities less than 3 hours/week
0	1	2	3	4

29. **Managing money and finances** – shopping, keeping a check book or other bank accounts, managing personal income and investments; if independent with small purchases but not able to manage larger personal finances or investments, rate 3 or 4.

Independent, manages small purchases and personal finances without supervision from others	Manages money independently but others have concerns about larger financial decisions	Requires a little help/supervision (5-24% of the time) with large finances; independent with small purchases	Requires moderate help/supervision (25-75% of the time) with large finances; some help with small purchases.	Requires extensive help/supervision (more than 75% of the time) with large finances; frequent help with small purchases
0	1	2	3	4

For the following items, please answer in regards to your relationship **AFTER the injury**.

1. Please indicate the degree of happiness, all things considered, of your relationship **after the injury**:

Extremely Unhappy	Fairly unhappy	A little unhappy	Happy	Very Happy	Extremely Happy	Perfect
0	1	2	3	4	5	6

Most people have disagreements in their relationships. Please indicate below the proximate extent of agreement or disagreement between you and your partner **after the injury** for each item:

	Always disagree	Almost always disagree	Frequently disagree	Occasionally disagree	Almost always agree	Always agree
2. Amount of time spent together	0	1	2	3	4	5
3. Making major decisions	0	1	2	3	4	5
4. Demonstration of affection	0	1	2	3	4	5

	Never	Rarely	Occasionally	More often than not	Most of the time	All of the time
5. In general, how often do you think things between you and your partner are going well?	0	1	2	3	4	5
6. How often do you wish you had not gotten into this relationship?	0	1	2	3	4	5

For the following items, please answer in regards to your relationship **AFTER** the injury.

	Not at all true	A little true	Somewhat true	Mostly true	Almost completely true	Completely true
7. I feel a strong connection with my partner.	0	1	2	3	4	5
8. If I had my life to live over, I would marry/live with/date the same person.	0	1	2	3	4	5
9. Our relationship is strong.	0	1	2	3	4	5
10. I sometimes wonder if there is someone else out there for me.	0	1	2	3	4	5
11. My relationship with my partner makes me happy.	0	1	2	3	4	5
12. I have a warm and comfortable relationship with my partner.	0	1	2	3	4	5
13. I can't imagine ending my relationship with my partner.	0	1	2	3	4	5
14. I feel that I can confide in my partner about virtually anything.	0	1	2	3	4	5
15. I have had second thoughts about this relationship recently.	0	1	2	3	4	5
16. For me, my partner is the perfect romantic partner.	0	1	2	3	4	5
17. I really feel like part of a team with my partner.	0	1	2	3	4	5
18. I cannot imagine another person making me as happy as my partner does.	0	1	2	3	4	5

For the following items, please answer in regards to your relationship **AFTER the injury**.

	Not at all	A little	Somewhat	Mostly	Almost Completely	Completely
19. How rewarding is your relationship with your partner?	0	1	2	3	4	5
20. How well does your partner meet your needs?	0	1	2	3	4	5
21. To what extent has your relationship met your original expectations?	0	1	2	3	4	5
22. In general, how satisfied are you with your relationship?	0	1	2	3	4	5

	Worse than all others (extremely bad)					Better than all others (extremely good)
23. How good is your relationship compared to most?	0	1	2	3	4	5

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
24. Do you enjoy your partner's company?	0	1	2	3	4	5
25. How often do you and your partner have fun together?	0	1	2	3	4	5

Mark the box that best describes *how you feel about your relationship*. Consider "in between" boxes too. Base your responses on your first impressions and immediate feelings about the item.

26. INTERESTING							BORING
27. BAD							GOOD
28. FULL							EMPTY
29. LONELY							FRIENDLY
30. STURDY							FRAGILE
31. DISCOURAGING							HOPEFUL
32. ENJOYABLE							MISERABLE

The Impact of Traumatic Brain Injury (TBI) on Romantic Relationships – Interview for Survivor

6. For the purpose of this study, do you identify as: (circle a or b)
 - a. Having sustained a TBI, personally
 - b. A romantic partner of an individual who has sustained a TBI
 7. When did your romantic relationship, at the time of injury, begin (mm/yyyy)? _____
 8. Are you currently in the same romantic relationship as at the time of injury?
 9. When did your (or your partner's) TBI occur (mm/yyyy)? _____
-

1. Absentmindedness:
 - a. Are you absentminded or could you be called a scatterbrain? Do you remember things at the wrong time or in a haphazard manner which makes memory inefficient?
 - b. For example, you might be sent to the store to buy bread, and will return with a full tank of gas and other errands completed, but only remembers the bread once you are home.
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
2. Indecisiveness:
 - a. Do you have difficulty making decisions, even simple ones?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
3. Non-Spontaneity:
 - a. Compared to before your head injury, do you seem to initiate fewer behaviors on your own? If left to yourself, would you just lie around?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
4. Perplexity:
 - a. Do small changes of plan or topics of conversation confuse you? Do you often feel like you have a “one track mind”?
 - b. Do you find it difficult to adapt to changes in an environment?
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
5. Apparent low motivation:
 - a. Do you feel motivated to return to work or “be normal again”?
 - b. Do you feel lazy or unambitious, compared to before your injury?
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
6. Disorganization:
 - a. Do you have difficulty getting organized to complete even the simplest of tasks? Even if it is something you used to be able to do quite easily?
 - b. For example, are you unable to tune the car radio even if someone tells you to do so?
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?

7. Inflexibility:
 - a. Do you insist that things are done the same way every time, over and over again? If there is any deviation from how things are traditionally done, how do you react?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
8. Poor planning and anticipation:
 - a. Do you make reasonable plans before acting or speaking?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
9. Failure to learn from experience:
 - a. Do you tend to make the same mistakes over and over?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
10. Poor judgement:
 - a. We all make little decisions every day, such as the order in which daily chores are performed, what to purchase at the store, or how our time should be allocated. Does it seem like you routinely make poor decisions in planning or executing these activities of daily living?
 - b. For example, even though you have good intentions, are tasks done at inappropriate or undesirable times, or done by inefficient means, when a better option was clearly available?
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
11. Non-Reinforcing:
 - a. Do you find yourself no longer doing the “little things” for your partner? Do you feel like you can tend to act neutral to your partner?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
12. Risk seeking behavior:
 - a. Do you enjoy taking unnecessary risks “just for the fun of it”? This may be particularly evident in driving).
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
13. Disinhibition:
 - a. Do you do things in public that may be embarrassing or not appropriate? These things may be described as “things you/he/she just couldn’t resist doing”.
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
14. Impulsivity:
 - a. Do you sometimes act impulsively? In other words, do you sometimes act first and think later, without considering the consequences? This may be most evident in driving, spending or casual conversation.
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?

15. Impolitic speech:

- a. Do you stick your foot in your mouth more often than you used to?
- b. How do you feel this symptom has impacted your relationship?
- c. What strategies have you employed to adjust to this tendency?

16. Neutral affect:

- a. Do you feel as if you have no affect or emotion at all?
- b. How do you feel this symptom has impacted your relationship?
- c. What strategies have you employed to adjust to this tendency?

17. Poor insight

- a. Do you ever feel to have a poor understanding of yourself, your behaviors, emotions or limitations?
- b. Do you understand the psychological or mental changes you have suffered from your brain injury?
- c. How do you feel this symptom has impacted your relationship?
- d. What strategies have you employed to adjust to this tendency?

18. Poor empathy

- a. Since the head injury are you worse at understanding your partner's feelings?
- b. Do you have a harder time seeing your partner's perspective on things?
- c. How do you feel this symptom has impacted your relationship?
- d. What strategies have you employed to adjust to this tendency?

19. Physical intimacy:

- a. How did your brain injury affect your physical intimacy?
- b. What strategies have you employed to adjust to this?

The Impact of Traumatic Brain Injury (TBI) on Romantic Relationships – Interview for Caregiver

1. For the purpose of this study, do you identify as: (circle a or b)
 - a. Having sustained a TBI, personally
 - b. A romantic partner of an individual who has sustained a TBI
 2. When did your romantic relationship, at the time of injury, begin (mm/yyyy)? _____
 3. Are you currently in the same romantic relationship as at the time of injury?
 4. When did your (or your partner's) TBI occur (mm/yyyy)? _____
-

1. Absentmindedness:
 - a. Is your partner absentminded or could be called a scatterbrain? Does your partner remember things at the wrong time or in a haphazard manner which makes memory inefficient?
 - b. For example, you might send him/her to the store to buy bread, and he/she will return with a full tank of gas and other errands completed, but only remembers the bread once he/she is home.
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
2. Indecisiveness:
 - a. Does your partner have difficulty making decisions, even simple ones?
 - b. Does your partner let you to make decisions for him/her now, that he/she may not have before the injury?
 - c. Do you sometimes feel responsible for most daily household decision making as well as the larger decisions? (examples: what to watch on TV, what to have for dinner)
 - d. How do you feel this symptom has impacted your relationship?
 - e. What strategies have you employed to adjust to this tendency?
3. Non-Spontaneity:
 - a. Compared to before his/her head injury, does your partner seem to initiate fewer behaviors on their own? If left to himself/herself, would he/she just lie around?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
4. Perplexity:
 - a. Can your partner become very confused by small changes of plan or topics of conversation because he/she has a “one track mind”?
 - b. Does your partner find it difficult to adapt to changes in an environment?
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
5. Apparent low motivation:
 - a. Does your partner seem motivated to return to work or “be normal again”? Does he/she appear lazy, unmotivated or unambitious to others?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?

6. Disorganization:
 - a. Does your partner have difficulty getting organized to complete even the simplest of tasks, because he/she is inefficient, doesn't carry out plans that are made, etc? Even if it is something he/she used to be able to do quite easily?
 - b. For example, is your partner unable to tune the car radio even if someone tells you/him to do so?
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
7. Inflexibility:
 - a. Does your partner insist that things are done the same way every time, over and over again? If there is any deviation from how things are traditionally done, how does he/she react?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
8. Poor planning and anticipation:
 - a. Does your partner act in a manner that suggests he made a plan of action prior to acting or speaking?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
9. Failure to learn from experience:
 - a. Does your partner seem to make the same mistakes over and over? Does your partner fail to learn from experience?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
10. Poor judgement:
 - a. We all make little decisions every day, such as the order in which daily chores are performed, what to purchase at the store, or how our time should be allocated. Does it seem like your partner routinely makes poor decisions in these activities of daily living?
 - b. For example, even though he/she may have good intentions, are tasks done at inappropriate or undesirable times, or done by inefficient means, when a better option was clearly available?
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
11. Non-Reinforcing:
 - a. Does your partner seem to have a rather neutral attitude toward you? While not meaning to be rude, does he fail to do the "little things" which make a person feel loved or appreciated?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
12. Risk seeking behavior:
 - a. Does your partner seem to enjoy taking unnecessary risks "just for the fun of it"? This may be particularly evident in driving).
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?

13. Disinhibition:
 - a. Does your partner do things in public that are embarrassing or inappropriate? These things may be described as “things you/he/she just couldn’t resist doing”.
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
14. Impulsivity:
 - a. Does your partner sometimes act impulsively? In other words, does your partner sometimes act first and think later, failing to consider the consequences? This may be most evident in driving, spending or casual conversation.
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
15. Impolitic speech:
 - a. Does your partner stick his/her foot in his/her mouth more often than he used to?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
16. Immaturity/childlike dependence:
 - a. Do you feel as if there is one more child in your home since your partner’s injury? Do you sometimes feel as if you are the only parent or responsible adult at home?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
17. Neutral affect:
 - a. Does your partner appear to have no affect or emotion at all? Is he/she inanimate, sort of like a piece of furniture is inanimate?
 - b. How do you feel this symptom has impacted your relationship?
 - c. What strategies have you employed to adjust to this tendency?
18. Poor insight
 - a. Does your partner seem to have a poor understanding of him or herself, behaviors, emotions or limitations?
 - b. Does your partner understand the psychological or mental changes he/she has suffered from the brain injury?
 - c. How do you feel this symptom has impacted your relationship?
 - d. What strategies have you employed to adjust to this tendency?
19. Poor empathy
 - a. Since the head injury, is your partner worse at understanding how you are feeling?
 - b. Does your partner have harder time seeing your perspective on things?
 - c. Does he seem to not even consider that you may have feelings or opinions on certain subjects?
 - d. How do you feel this symptom has impacted your relationship?
 - e. What strategies have you employed to adjust to this tendency?
20. Self-centeredness:
 - a. Has your partner become self-centered, without becoming highly selfish? That is, while appreciating his/her own point of view or needs, does he/she fail to appreciate that others may have similar feelings?
 - b. How do you feel this symptom has impacted your relationship?

- c. What strategies have you employed to adjust to this tendency?
21. Physical intimacy:
- a. How did your partner's brain injury affect your physical intimacy?
 - b. What strategies have you employed to adjust to this?

Appendix B

Table B3. *Change in CSI Scores, by Item – Total*

	Change in response; pre-post (n=41)	Significance (p-value)
1. Degree of happiness, all things considered	1.780	0.000*
2. Amount of time spent together	.854	0.000*
3. Making major decisions	.902	0.000*
4. Demonstration of affection	1.854	0.000*
5. How often do you think things between you and your partner are going well?	.780	0.000*
6. How often do you wish you had not gotten into this relationship?	.610	0.010*
7. I feel a strong connection with my partner.	1.244	0.000*
8. If I had my life to live over, I would marry/live with/date the same person.	.829	0.001*
9. Our relationship is strong.	1.220	0.000*
10. I sometimes wonder if there is someone else out there for me.	.122	0.689
11. My relationship with my partner makes me happy.	1.390	0.000*
12. I have a warm and comfortable relationship with my partner.	1.415	0.000*
13. I can't imagine ending my relationship with my partner.	.829	0.002*
14. I feel that I can confide in my partner about virtually anything.	1.195	0.000*
15. I have had second thoughts about this relationship recently.	.390	0.150
16. For me, my partner is the perfect romantic partner.	1.341	0.000*
17. I really feel like part of a team with my partner.	1.780	0.000*
18. I cannot imagine another person making me as happy as my partner does.	1.244	0.000*
19. How rewarding is your relationship with your partner?	1.341	0.000*
20. How well does your partner meet your needs?	1.439	0.000*
21. To what extent has your	1.244	0.000*

relationship met your original expectations?		
22. In general, how satisfied are you with your relationship?	1.415	0.000*
23. How good is your relationship compared to most?	1.171	0.000*
24. Do you enjoy your partner's company?	1.146	0.000*
25. How often do you and your partner have fun together?	1.195	0.000*
26. Interesting....Boring	1.585	0.000*
27. Bad...Good	1.610	0.000*
28. Full...Empty	2.000	0.000*
29. Lonely...Friendly	2.049	0.000*
30. Sturdy...Fragile	1.707	0.000*
31. Discouraging...Encouraging	1.756	0.000*
32. Enjoyable...Miserable	1.610	0.000*

Table B5. *Post-injury Couples Satisfaction Index (CSI) Scores, by Item – Survivor vs. Caregiver*

	Survivor (n=22)	Caregiver (n=19)	Significance (p-value)
1. Degree of happiness, all things considered	3.23	2.37	0.089*
2. Amount of time spent together	3.14	2.58	0.076*
3. Making major decisions	3.14	2.74	0.295
4. Demonstration of affection	2.64	1.74	0.079*
5. How often do you think things between you and your partner are going well?	3.14	3.21	0.816
6. How often do you wish you had not gotten into this relationship?	4.27	3.68	0.182
7. I feel a strong connection with my partner.	3.45	3.37	0.849
8. If I had my life to live over, I would marry/live with/date the same person.	3.73	3.63	0.857
9. Our relationship is strong.	3.23	3.58	0.450
10. I sometimes wonder if there is someone else out there for me.	3.86	4.05	0.725
11. My relationship with my partner makes me happy.	3.27	2.95	0.471
12. I have a warm and comfortable relationship with my partner.	3.09	2.84	0.592

13. I can't imagine ending my relationship with my partner.	4.00	3.74	0.619
14. I feel that I can confide in my partner about virtually anything.	3.36	2.58	0.140
15. I have had second thoughts about this relationship recently.	3.86	3.74	0.834
16. For me, my partner is the perfect romantic partner.	3.32	2.42	0.081*
17. I really feel like part of a team with my partner.	2.95	2.42	0.337
18. I cannot imagine another person making me as happy as my partner does.	3.50	2.95	0.313
19. How rewarding is your relationship with your partner?	3.14	2.89	0.594
20. How well does your partner meet your needs?	3.41	2.11	0.004*
21. To what extent has your relationship met your original expectations?	3.18	2.63	0.264
22. In general, how satisfied are you with your relationship?	3.05	2.79	0.594
23. How good is your relationship compared to most?	3.18	3.00	0.718
24. Do you enjoy your partner's company?	4.14	3.21	0.083*
25. How often do you and your partner have fun together?	2.95	2.74	0.647
26. Interesting....Boring	3.41	2.42	0.044*
27. Bad...Good	3.45	3.05	0.458
28. Full...Empty	2.95	2.21	0.138
29. Lonely...Friendly	2.82	2.26	0.312
30. Sturdy...Fragile	3.05	2.63	0.482
31. Discouraging...Encouraging	3.09	2.84	0.645
32. Enjoyable...Miserable	3.14	2.84	0.547

Appendix C

Table C9. *Emergent Themes from Interviews, Supporting Quotes*

Theme	Supporting Quotes
Changes in self (survivor)	<ul style="list-style-type: none"> • “Now I don’t know myself. I live in someone else’s world, someone else’s body. I can see my old self, but it is cloudy on how to get back to that.” – Survivor • “I was always energetic. I never said no. I was accomplished. I always had so many balls in the air. I could never imagine that life now.” – Survivor • “I used to know my husband really well; I always knew what he was thinking and what he needed. I could anticipate his feelings, needs and desires. I’m not on the ball like I used to be.” – Survivor • “I feel like a duck swimming in the water. Underneath, legs are moving 100 miles per hour, but on top, people only see the duck just floating along calmly. That’s what life is for me now, and even my husband doesn’t see how much harder I have to work just to live.” – Survivor • “I’ve become reclusive, introverted, flat. I don’t feel anything anymore.” – Survivor • “I don’t know who I am anymore. I just exist.” – Survivor • “I spend my entire day concentrating so hard on making sure I get through the next minute that those things are not in my brain.”
Effect on relationship	<ul style="list-style-type: none"> • “I frustrate him terribly.” – Survivor • “[The relationship] was even before, like 50-50. Now it is 90-10.” – Survivor • “I don’t hold up my end anymore.” – Survivor • “After the injury you’re dealing with so much: the pain, rehabilitation, appointments, medications, tests, buying a new car, fighting with insurance companies. I don’t know what comes first, the chicken or the egg. Is it the injury or all the stuff that comes with it? All of a sudden it’s not the same and you don’t know when it stopped being the same.” – Survivor • “We don’t have a romantic relationship anymore. That was taken

from me the day of my accident...That was the worst thing I lost.”
– Survivor

- “It has changed the dynamic of the relationship. We used to be husband and wife, equal partners. Now I’m like her kid. That’s not romantic.” – Survivor
- “My thoughts in my mind take so much energy that I really do not have the energy to incorporate another person into that moment.” – Survivor
- “I have vertigo from the brain injury, which takes the spontaneity out of everything.” – Survivor
- “There are still kisses, hugs and cuddling, but...a relationship with sex, that’s over. It hasn’t happened since the accident. I don’t like to think about it. It’s too big, too painful and makes me feel inadequate.” – Survivor
- “I want someone to play with. I don’t have a buddy anymore.” – Caregiver
- “Sex has become so careful and calculated. Avoiding certain positions takes away the naturalness of sex...it puts a divide between us.” – Caregiver
- “I have to make all the decisions...it’s like a parent-child, doctor-patient relationship instead of an equal partnership.” – Caregiver
- “It’s definitely not romantic having to be like a parent explaining to a child how things work, why we’re doing it this way, etc. and doing that in a non-condescending and respectful manner to your [partner].” – Caregiver
- “If I ever want to go out to dinner or have a date night, that would be something I’d have to plan and drag him to.” – Caregiver
- “It’s isolating. He’s not there interacting with me.” – Caregiver
- “I don’t get to take time off. I have to be ‘on’ all the time.” – Caregiver

Strategies

- “I write everything down! Every morning I have to make a list of everything to do that day, and I organize it by priority, and in the evening if anything hasn’t gotten done I start a new list for the next
-

day.” – Survivor

- “I calmly talk myself into things. If he initiates anything, even sex, I go along with it. I talk myself down from the anxiety, and in five minutes I’m okay and I’m enjoying it.” – Survivor
- “I’ve learned what I can cope with. We pay someone to clean the house now. We eat out more than we used to. I don’t change the sheets every 3-4 days; I change them ever 7-8 days.” – Survivor
- “I have to apologize a lot [for things I say], but he is very good about giving me a second chance to say it right. He is very understanding and patient.” – Survivor
- “We schedule a movie night or game night regularly.” – Survivor
- “We tell each other, ‘It’s going to be okay in the end. We’re going to get there,’ and that we love each other, and that this is the definition of... ‘for better or for worse.’” – Survivor
- “Everything is on the calendar now.” – Survivor
- “Acceptance. It is what it is.” – Caregiver
- “We pick each other up; I pick up the slack. I remind myself she is doing the best she can, I accept where she’s at and choose to focus on her 40 other good qualities.” – Caregiver
- “I try not to wear the doctor hat all the time. Sometimes I just need to be her husband.” – Caregiver
- “We have a list of restaurants and fun activities written on index cards, and he can pick one out on the night of the week we’ve set aside for that.” – Caregiver
- “Our communication strategy is to mirror what the other person is saying to check for understanding and to validate and empathize with their experience. He’ll say I’m being condescending or bossing him around, and I’ll have to mirror or repeat that back so he knows I understand his experience.” – Caregiver

Advice

- “You have to have three keys to make it work. You still have to love each other; one of you has to be an excellent communicator; there has to be patience.” – Survivor
 - “Don’t make any judgments or any decisions until you’re way
-

down the road because so much changes, so many times, so drastically.” – Survivor

- “Don’t quit. It does get better. You find the new dance, the new rhythm between you. It’s a new relationship but you find your way.” – Survivor
 - “Forget about each week, each month, each year. It’s about surviving each day and each interaction between you.” – Caregiver
 - “You can mourn the past, but you can’t live in it.” – Caregiver
 - “[Your partner] isn’t doing it to piss you off; it’s the brain injury.” – Caregiver
 - “I don’t think they address it at all. Even when we were going through the lawsuit, [my husband] and I both explained how badly this affected our personal selves and personal relationship, and they just blew that off. I think it makes them uncomfortable, but it’s huge.” – Survivor
 - “Nobody deals with the emotional aspect.” – Survivor
 - “We’re not even part of the equation, but we’re doing everything.” – Caregiver
 - “You get these generic sections in a book saying, ‘you will experience these things...’” – Caregiver
 - “Nothing has been addressed in terms of our relationship. I would have loved someone to explain things to me, like why my wife is different, why she does certain things. I’d like to know if this is normal or common after a brain injury.” – Caregiver
 - “Education is such a huge missing part of treatment. Caretakers already feel totally burdened and isolated, and they get nothing from doctors.” – Caregiver
-

Content with
Professionals