Exploring Intimacy After Traumatic Brain Injury (TBI)
for TBI Survivors and Their Partners

BY

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THESIS
Submitted as partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Disability Studies
in the Graduate College of the
University of Illinois at Chicago, 2012

Chicago, Illinois

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ACKNOWLEDGMENTS

I would like to thank my graduate advisor and research mentor, Dr. Carol J. Gill, for her incredible knowledge, insight, support, and patience throughout this process. She encapsulates the essence of what I imagine an outstanding mentor should be. I am extremely grateful and honored to have the opportunity to know her.

I would also like to thank my dissertation committee, Drs. Tamar Heller, Joy Hammel, Teresa Savage, and Debi Mukherjee, for their unwavering support, guidance, and expertise through all phases of this research project.

Lastly, I would like to extend heartfelt appreciation to all the couples who participated in this project. Their perspectives were invaluable and contributed to a deeper understanding of the issues. Without their participation, this research would not have been possible.

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SUMMARY

An exploratory qualitative study was conducted to examine the experience of intimacy following traumatic brain injury (TBI) for TBI survivors and their partners. Participation in a meaningful personal relationship has been correlated with perceived positive quality of life for TBI survivors and their partners (Kreuter, Dahllof, Gudjonsson, Sullivan, & Siosten, 1998). Although social relationships and brain injury are well-documented in the TBI literature, research exploring the impact of TBI on intimate relationships is scarce (Gaudet, Crethar, Burger, & Pulos, 2001).

This research study was informed by a social model of disability framework that encompasses the social as well as physiological aspects of the TBI experience and acknowledges the need to explore the socio-political gaps in the current health care system of TBI rehabilitation. This study focused on capturing positive as well as challenging factors of intimacy after TBI, thus departing from a “tragedy” view of disability (Crisp, 2002).

Multiple qualitative methods, including initial and follow-up interviews and focus groups, were utilized with thirteen couples in which one partner had sustained a TBI. Couples were recruited primarily from rehabilitation facilities and community support groups in the Chicago, Illinois area. The constellation of the couples included married, unmarried, heterosexual, and same-sex partnerships for the purposes of gaining information from people of multiple backgrounds and experiences. Initial in-depth interviews and follow-up interviews six months later were conducted in an effort to understand how the passage of time affected intimacy. At the end of the data collection period, separate focus groups for survivors and partners were conducted to share preliminary themes with participants and to obtain their feedback and further insights pertinent to the study.
SUMMARY (continued)

Results of the study revealed that intimacy after TBI is a highly complex phenomenon that is not easily interpreted within existing TBI and relationship research. In this research, issues of relationship fragility were balanced against stability, especially as couples moved beyond the initial stages of injury. Relationship resilience was a common thread throughout this research, but it was influenced by the quality and types of social support available to participants. Also, factors such as societal misconceptions of TBI and comparisons to pre-injury selves threatened to thwart positive adaptation and relationship strength.

Recommendations for future research include conducting continued in-depth exploration of intimacy after TBI with larger numbers of participants in order to further understand the factors that contribute to positive adjustment for couples. Further investigation of the relationship between pre-injury psychological coping skills and relationship well-being after TBI is also recommended in order to identify high-risk couples in need of specialized intervention. In addition, further study is needed to discern the potential of social peer support interventions to empower couples to reconstruct their relationships in a positive way. The need for increased education about TBI couples for health care professionals and society at large is emphasized in order to support ongoing awareness of intimacy and TBI as an important social issue.
I. INTRODUCTION

A. Background

Traumatic brain injury (TBI) can be a devastating experience for survivors and their families or significant others (Liss & Willer, 1990). Life roles are often profoundly altered after TBI. A major social role that may be affected is involvement in an intimate relationship, including marriage. TBI research indicates that being in a meaningful personal relationship directly correlates with positive perceived quality of life for brain injury survivors and their partners (Kreuter, Dahllof, Gudjonsson, Sullivan, & Siosten, 1998). However, there has been little attention in the TBI research literature to the specific exploration of intimate interpersonal relationships. Certainly if families as well as survivors are affected after TBI, intimate relationships must weather significant challenges.

One can appreciate the social implications of this problem when the incidence of TBI is considered. Miller (1994) identified long-term disability associated with TBI and also emphasized the need for long-term supports and services for survivors and their caregivers, estimating that 3.17 million individuals live with TBI-related disability in the United States. Corrigan, Selassie, and Orman (2010) developed a model to predict long-term disability following TBI. They found that approximately 235,000 Americans are hospitalized with non-fatal traumatic brain injuries annually and will likely need long-term support and rehabilitation in order to minimize the adverse effects on survivors, their families, and society. A recent qualitative investigation seeking survivor and family perceptions of services after hospitalization (Turner, Fleming, Ownsworth, & Cornwell, 2011) indicated that existing service models are insufficient for meeting their complex and long-term needs throughout TBI adjustment.
Furthermore, results indicated that inadequate and inconsistent supports after acute TBI care can potentially obstruct successful adaptation following TBI. A more comprehensive understanding of issues affecting the relationships of survivors and their partners throughout the trajectory of TBI adjustment will facilitate more effective interventions at each stage.

From a more personal perspective, my career as an occupational therapist exposed me to many families negotiating life with a newly acquired illness or injury. One TBI survivor and his wife, in particular, made an impression on me over a decade ago that has shaped my current research interests and goals. My patient was a young man in his thirties who sustained a TBI from a fall at work. His memory and reasoning were significantly impaired but he possessed a wry sense of humor and kindness that intrigued me as to what he was like as a husband, a friend and father prior to his injury. I came to know his wife who attended as many treatment sessions as she could manage between her work and taking care of two small children. She shared many stories about how she felt their communication was vastly different and how the relationship had deteriorated since her husband’s accident. My patient, on the other hand, often referred to his family life as “pretty much the same” when asked what he felt was different at home since his injury. Consequently, he often demonstrated confusion and frustration regarding the challenges his wife expressed to him and to the treatment team. At the time of his discharge from therapy, this couple’s conflicts had mounted to the extent that the wife was considering divorce. I stayed in touch with them for a while afterwards and learned that they had stayed together, but the daily challenges and conflicts were worse than ever. Their future together remained uncertain.

I eventually lost touch with them but I often wish that I had asked them about the types of support they had to fall back on or what experiences they shared together that helped to sustain
them in difficult times. How do we, as health professionals, help pave the way for couples to
smooth the potentially rough road ahead of them?

The recent media attention spotlighting congresswoman Gabrielle Giffords, TBI survivor,
and her husband, astronaut Mark Kelly, bring to mind questions about whether having financial,
political and personal resources help to shield and protect couples from future breakdown in their
relationships. The photographs and videos portray congresswoman Giffords and her husband as
loving and happy and, so far, coping well with the challenges that are associated with being in a
relationship with a partner with a TBI. These images, though, are just that. We are not privy to
their day to day life together or to any difficulties they might confront in the future. What do we
really know about what factors contribute to relationship stability or fragility in the long term?
How is the continuity of relationships most optimally addressed? If public support is critical to
adjustment, then how do couples who come from a range of backgrounds and opportunities
handle the aftermath of brain trauma? This research is an attempt to explore these issues in depth
and detail in order to shed some light on this emerging social and personal problem.

B. **Organization of Project**

Following this introductory chapter, the paper is organized into five remaining chapters
that are described below.

Chapter two introduces the existing TBI and relationship literature and some theoretical
writing that has significance for intimacy and TBI. Additionally, this chapter identifies some of
the gaps in current TBI and relationship research.

Chapter three expands upon the discussion of gaps in the existing research and describes
how this study attempts to address these gaps. This chapter describes the purpose, conceptual
frameworks, and research questions that guide this study.
Chapter four describes the methods used to execute this research. The study design, data collection, and analysis procedures are covered.

Chapter five reports the results of the study and describes major themes and subthemes emerging from the data. Within this chapter, themes are synthesized into findings regarding how intimacy is experienced by the couples who participated in this research.

Chapter six discusses the study’s findings further and situates them within the context of the relevant research literature. The ways in which these findings confirm, challenge, and extend the intimacy and TBI literature are examined. Suggestions for future research and interventions for people with TBI and their partners are discussed at the conclusion of this chapter.
II. REVIEW OF THE LITERATURE

A. Introduction to the Literature

In the following subsections, I address research and theoretical writing from the TBI and relationship literature. I also describe concepts from the general intimacy literature that have relevance to intimate relationships for couples experiencing TBI. Concluding each section, I briefly summarize the key points that offer insights about the issues. At the conclusion of this chapter, I provide a conceptual framework drawn from the major highlights of the literature in which to provide a context for the current study.

B. Role Change and Loss Affecting Intimacy

Intimate and sexual role disturbances have been examined and substantiated in the TBI marital relationship research. The scope of research exploring intimacy has been tipped in favor of hypothesizing for impairment or loss as opposed to imagining the broader social and interpersonal dynamics after TBI (Gaudet et al., 2001). There is limited research incorporating group and/or individual open-ended interviews, and few engage in dialogue with both survivors and uninjured partners to gain a more comprehensive understanding of their experiences. This is unfortunate because TBI survivors have not historically had many, if any, opportunities to voice their views in research on topics such as sexuality and intimacy.

1. Loss Associated with the Survivor’s TBI-related Impairment

The TBI literature has tended to characterize post-injury changes in terms of loss and has lacked any affirmative view of the altered self of the TBI survivor or even accounts from survivors that shed light on their experiences (Hill, 1999; Crisp, 1993). For instance, in a retrospective inquiry of TBI and intimacy research, Liss and Willer (1990) found role change
and loss to be the most prevalent long-term complaint of uninjured significant others (at least nine months post injury), which was associated with survivors’ cognitive, emotional, and behavioral deficits. A common theme in the literature, according to the authors, is the idea that uninjured partners grieve the loss of their once primary source of emotional support and companionship just at a time when it is most needed. At the same time, because grieving for the loss of a person still present is not considered socially acceptable, there is felt conflict between grieving and guilt (Liss & Willer, 1990).

Wood and Yurdakul (1997) examined the neuropsychological effects of TBI on personal relationships by collecting survey data from 350 uninjured partners over a four-year period. Fifty-four percent of respondents indicated that relationship failure was a result of personality changes and cognitive deficits. After 2.5 years, 48 of the partners completed a 12-item measure rating how neurobehavioral characteristics impacted their relationship with their injured partners. Results of the study indicated that neither severity of injury nor length of time since injury determined relationship stability. Instead, partners cited unpredictable patterns of behavior as the most detrimental factor to the longevity and health of their personal relationships. The authors concluded that there is a critical need to develop therapeutic interventions that assist uninjured partners to cope with difficult behaviors after TBI.

The question of whether sexuality and intimacy problems are already present during the acute TBI rehabilitation phase was investigated by Aloni et al. (1999). They utilized a psychosexual questionnaire that encompassed questions about sexual behavior, self-esteem, and relationships and obtained responses from 44 male TBI patients in a rehabilitation center. Their findings indicated that only 14% of the respondents who demonstrated severe brain injury admitted to experiencing sexual dysfunction. The authors hypothesized that sexual disturbances
would most likely emerge after the initial rehabilitation phase when significant others had more time to realize the possible permanence of their partners’ deficits (Aloni et al., 1999).

Layman, Dijkstra, and Ashman (2005) examined the impact of TBI on the lived experience of couples in which one partner sustained a TBI. Responses from open-ended interviews with uninjured partners indicated that issues such as diminished sexual relations and overall energy were expressed, but it was difficult for participants to determine what factors were affected by the TBI and which were associated with normal aging. Further examination was recommended in order to increase appreciation of unique issues for older couples experiencing TBI. Longitudinal research into improvements in individual and family functioning over time could be helpful in validating the costs of caring for an increasingly older population of TBI survivors.

2. **Role Change and Marital Vulnerability/Quality**

It is generally agreed that spouses of TBI survivors experience greater and longer-lasting stress than do other close associates of TBI survivors (Blais & Boisvert, 2005; Leathem, Heath, & Woolley, 1996). For example, Leathem et al. (1996) compared perceptions of role change and stress after TBI between parents and spouses of TBI survivors. Both groups were asked to report the types and degree of role change they experienced since their loved ones’ injury, types of social support they experienced or felt they needed, perceptions of health since their relative’s TBI, and their level of difficulty in maintaining a positive relationship with their loved one while attempting to negotiate daily tasks and leisure pursuits. Responses from all measures were based on Likert type scales. The greatest change in roles was reported to be in their relationships with their loved ones, especially by the partner group. They also reported that social aspects such as pursuing recreational and leisure activities were significantly diminished since TBI. It was also
found that partners experienced a greater degree of health problems as compared with parents. The most prevalent source of stress reported by the mostly female uninjured partners was related to home maintenance, financial, and work categories. However, in a cross-sectional design study, Kreutzer, Kolakowsky-Hayner, Demm, and Meade (2002) found that differences in distress levels among spouses, parents, and other caregivers were not significant. Caregiver distress levels were mitigated by the emotional and behavioral status of survivors and whether survivors were engaged in some type of productive paid or volunteer work. The concepts of intimacy and sexuality are very personal, and therefore, are more likely to be understood comprehensively through qualitative exploration that reflects the first-hand accounts of both partners (Brown & Gordon, 2004; Gosling & Oddy, 1999; Kreuter et al., 1998; Nochi, 1997; Nochi, 1998; Hill, 1999). For example, Kravetz et al.(1995) investigated marital vulnerability and self-concept of couples in which the male spouse had sustained a TBI. They asked both partners as well as a control group of uninjured couples to complete two questionnaires regarding marital vulnerability and self-concept. Interestingly, wives with partners with TBI reported less marital vulnerability as compared to a control group of wives with uninjured spouses. The former reported feeling less dependent on their loved ones and were less concerned if their relationships did not endure. Overall, the wives’ self-concept was reported as not affected by the fact that they experienced decreased marital vulnerability. In other words, the uninjured wives of husbands with brain injury did not feel that their partnership was a reflection of their selves. The group of injured husbands rated their self-esteem lower as compared to the control group of uninjured husbands, and they reported more marital vulnerability than husbands of the control group. However, uninjured wives reported more neuroses and general maladjustment than wives
in the control group, which the authors attributed to possible feelings of guilt and shame regarding their feelings about their husbands’ deterioration.

Gosling and Oddy (1999) undertook an in-depth study of 18 heterosexual couples to explore the quality of their marital and sexual relationships, one to seven years post TBI, from the perspectives of the uninjured partners, who were all women. Qualitative information gleaned through in-depth semi-structured interviews was utilized in addition to quantitative questionnaires designed to assess partners’ level of sexual and intimacy satisfaction since their spouse’s TBI. Respondents unanimously reported feeling as though they were forced into a maternal role engendered by their additional responsibilities, and this created a barrier to feelings of intimacy. Relationship changes were reported most predominantly as a loss of sharing or loss of equal partnership. Six of the 18 respondents described their sexual relationship as “feeling wrong” (p. 790). All respondents had difficulty identifying positive aspects of their relationships. However, nine respondents identified friendship and affection, and six mentioned feeling a sense of commitment to their partners.

Information on newly acquired responsibilities was important, according to Gosling and Oddy (1999), because this concept led to further discussion about the respondents’ perceived conflict between their caregiver and intimate partner roles. Although many of the participants admitted that their spouses expressed gratitude for their support, uninjured partners expressed lack of satisfaction with sexual and intimate expression. Their outlook for the future lacked optimism that their relationships would improve, although uninjured spouses were able to identify positive aspects of their relationships, such as commitment and companionship. The complexity of responses may have been heightened by the opportunity for participants to share their personal experiences of how their spouses’ TBI affected their relationships. Most of the
respondents also indicated that they were happy to have been asked to share their perspectives and felt that the experience was therapeutic (Gosling & Oddy, 1999). Future research was recommended to explore the concept of marital or other intimate relationship role incompatibility. Obtaining the perspectives of injured partners, especially women, was cited as important in order to increase attention to gender and intimacy issues.

Studies that have explored specific challenges after TBI survivors return home with their partners after hospitalization suggest an increase in and difference in the quality of problems experienced by both partners as compared to the initial hospital phase. Kreuter et al. (1998) investigated whether a correlation could be found between physical dependency on caregivers and sexual disturbances in the relationship, as reported by both partners. They hypothesized that people with TBI would experience lower self-esteem if they were physically dependent on their intimate partners at home and that negative self-esteem would lead to difficulties in their sexual relationship. Sixty-five males and 27 females who sustained a TBI from 1 to 20 years prior were asked to complete questionnaires pertaining to sexual adjustment, sexual interest, and satisfaction. Information on participants’ general health status and functional independence was also obtained. The respondents who were most dependent on their partners for daily activities and mobility also reported more difficulties with sexual ability and desire than previous to their injuries. These difficulties were associated with anxiety and other mood disturbances. Kreuter et al. (1998) recommended that professionals provide more information about sexuality and intimacy after TBI in an effort to reduce anxiety and self-doubt in survivors and their partners.

Glover (2003) conducted in-depth interviews with four men 6, 8, 10, and 11 years post TBI. The purpose of this study was to explore factors affecting long-term adjustment and quality of life after brain injury. All four participants were said to have “regular and ongoing contact”
for at least one year with an organization providing education, communication, interpersonal, and computer skill training, and social and leisure activities. They were also offered family support and assistance with medical and employment issues, as needed. Even with the organization involvement, all four men reported feeling a significant loss regarding their gender roles, social and family life, and employment that negatively affected their quality of life. However, the specific details, such as how often participants were able to take advantage of the programs offered by the organization were not described. The author did reiterate that long-term services for TBI survivors are significantly lacking. An ongoing longitudinal TBI continuum of care orchestrated by survivors, families, and professionals was recommended.

3. **Loss as Socially Constructed**

Historically, disabled people have been regarded as either asexual or sexually deviant (Anderson & Kitchin, 2000; Shakespeare, Gillespie-Sells, & Davies, 1996). In a study exploring barriers to sexuality education and training in Northern Ireland, 35 disabled people recounted their experiences through semi-structured interviews (Anderson & Kitchin, 2000). Interview findings indicated that both physical access and negative stereotypes about disabled people were barriers to engagement in meaningful intimate relationships for disabled people. If disability stereotypes can be a significant barrier to intimacy, persons with TBI may be at a particular disadvantage. TBI survivors and their families have limited visibility both in the general public and in the disability community; they consequently have few opportunities to convey realistic or positive perceptions of their lives to others. Furthermore, people with TBI may be particularly stigmatized for having cognitive deficits, a form of impairment that is widely devalued. People with cognitive disabilities are often assumed to be childlike, and therefore, may be even more likely to be considered asexual than people with primarily physical disabilities (Anderson &
Based on the results of their study, Anderson and Kitchin (2000) recommend sexuality and disability awareness training for professionals as well as survivors and families in order for disabled people to experience the same opportunities for sexual expression and participation as uninjured individuals.

Anderson and Kitchin (2000) further suggest that prevailing representations and myths of disabled people as not desiring or needing physical and emotional intimacy have contributed to the dearth of theoretical models to guide the study of these concepts in any depth. In addition, the authors note that sexual stereotypes about disabled people will continue to be perpetuated unless additional research is conducted to dispel these myths. According to Shakespeare et al. (1996) some disabled people may not have the language, confidence, or opportunity to discuss intimacy and sexual issues. Low expectations from family, peers, health care professionals, and other caregivers may contribute to this lack of opportunity (Shakespeare et al., 1996).

Compelling findings related to loss of self after TBI were reported by Nochi (1998), who explored the experiences of six male and four female TBI survivors through in-depth interviews. Three kinds of losses experienced by the respondents were loss of self-knowledge, loss by comparison to pre-injury selves, and loss of self “in the eyes of others” (Nochi, 1998, p. 873). The last type of loss reflects a larger social perspective on how disabled people are perceived. Nine respondents reported that they experienced daily stigmatization from society, making them feel inferior because of their brain injuries. They also stated that societal stereotypes interfered with their ability to form positive self-images (Nochi, 1998). Further, descriptive research highlighting personal stories of TBI was noted by the author as potentially useful in illustrating possible areas for more in-depth and longitudinal investigations (Nochi, 1998).
4. **Loss Associated with Health Professionals’ Low Expectations**

Pervasive negative stereotypes about people with TBI are, in part, perpetuated by health professionals who possess deeply seated assumptions that their patients’ quality of life is negatively correlated to the severity of their injury (Linden & Boylan, 2010; Redpath et al., 2010). For instance, Ernst, Trice, Gilbert, and Potts (2009) conducted a study to examine misconceptions about TBI among health professionals. One hundred and eight undergraduate nursing students completed a questionnaire regarding their understanding of TBI and recovery. Findings supported the hypothesis that even professionals who directly work with TBI survivors lacked fundamental knowledge in the areas of TBI recovery, brain damage, amnesia, and unconsciousness. These misconceptions are inadvertently transferred to survivors and families. In fact, two-thirds of respondents were reported to believe that full recovery from TBI is inevitable if the survivor wishes to recover badly enough. Respondents also reported that they often communicate these beliefs and others on a regular basis to patients and family members. Ernst et al. (2009) urged professionals to participate in specialized TBI educational sessions to reduce the likelihood of adversely influencing survivors and their intimate caregivers. They stated that misconceptions by health professionals have the potential to place undue stress on relationships that are already strained. Recommendations for increasing knowledge of brain injury included designing educational workshops that include information from first-person accounts of TBI experiences in an attempt to dispel faulty or limited understanding of TBI (Ernst et al., 2009).

Low expectations or inadequate understanding of how people with TBI adjust and change over time may negatively affect the types and quality of services and interventions designed and implemented for TBI survivors. Sadly, if someone is considered too severely damaged to benefit
from a particular service or resource, he or she could be left with few, if any, options to help adjust and adapt throughout the long recovery process. More specifically, in terms of intimacy, judgments by health care professionals or others may be made erroneously or prematurely, relegateing couples to view their relationships as inevitably doomed by TBI-related changes. As an example of this problem, Aloni et al.,(1999) express the idea that judgments about the TBI survivor’s potential and the potential of the relationship should be made early in the rehabilitation process:

> It is important to allow both partners to make their own free choice, whether they want to stay with each other or whether the new situation created by the injury does not fit in with their goals and wishes for their future. Partners should be able to reconsider the relationship after the early stage of the rehabilitation process, ascertaining if they can still benefit and receive gratification from the relationship. (p. 113)

Their synopsis reveals little understanding of the long adjustment process to TBI (Hill, 1999), including the possibility that people’s attitudes about their disabilities and their partners change with time and other extenuating factors. To suggest that couples should make such a significant and final decision so early in their rehabilitation period fails to acknowledge the non-linear process of adjustment to TBI (Hill, 1999).

Health care professionals’ attitudes towards survivors of TBI were investigated through the use of vignettes in which 460 nurses and doctors were asked to express their opinions about hypothetical survivors (Redpath et al., 2010). Four different injury scenarios were presented, including individuals who sustained injuries secondary to alcohol consumption, drug use, as a result of an aneurysm, and a motor vehicle accident that was caused by a drunk driver (not the survivor). The findings revealed that if a person was considered to have caused the injury they were at risk for being stigmatized and described more negatively. Moreover, the participants expressed less intention to assist persons who were blamed for their TBI. It was also found that
well-established doctors expressed more prejudicial attitudes than experienced nurses or doctors and nurses just entering these professions. Recommendations included replicating this study within actual clinical settings and specifying the factors on which respondents were basing decisions. Sensitivity training and education about TBI for health professionals was also deemed critical to providing more equitable and informed care to survivors and families (Redpath et al., 2010).

5. **Summary**

Although role change and loss after TBI are predominant themes in marital and TBI research, there is a lack of qualitative data describing the experience from the viewpoints of the people involved. Multiple types of loss for both partners have included loss related to survivor’s behavioral, emotional, and cognitive changes (Gosling & Oddy, 1999; Kravetz et al., 1995), role loss, loss of self-knowledge (Nochi, 1998), health care professionals’ decreased expectations (Redpath et al., 2010), and societal misunderstandings of TBI (Layman et al., 2005). A later consequence for both partners is exclusion and dwindling of affiliation to their communities. Thus, these problems further erode couples’ ability to ameliorate experiences of loss. In addition, they can promote scenarios for isolation that are potentially more detrimental to relationships than the actual impairments from TBI (Redpath et al., 2010).

C. **Stress and “Burden” Themes**

Issues of stress and “burden” are prevalent themes in the TBI and marital literature (Chwalisz, 1996; Katz, Kravetz, & Grynbaum, 2005; Leathem et al., 1996; Liss & Willer, 1990). Traditionally, it was assumed that TBI unambiguously exacted a negative toll or burden on the caregiver and relationship. Current research reflects a more nuanced view of positive as well as negative views of TBI, but this approach is still in development (Hammond, Davis, Whiteside,
Philbrick, & Hirsch, 2011; Levack, Kayes & Fadyl, 2010). Previous research has primarily focused on the caregiving spouse and has emphasized burden, and medical, psychological, and psychosocial impairments of survivors negatively affecting the family system (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011).

1. **Stress Exacerbated by Limited Resources**

The profound effect of stress and burden on spouses and significant partners is widely recognized. The multiple impacts of traumatic brain injury result in ongoing and daily challenges for families and survivors. Partners have reported feelings of hopelessness, overwhelming anxiety, anger, and depression (Wood & Yurdakul, 1997). These reactions do not necessarily dissipate with time, and in fact, may be exacerbated when services and support from the medical community diminish after formal rehabilitation is complete (Leith, Phillips, & Sample, 2004). Chenoweth and Stehlik (2004) reported that disabled people and their families are routinely excluded from activities such as community-level decision-making and program development. They also point to the fact that although family members take the responsibility for the majority of the care of their loved ones, these efforts go unrecognized in society. Daily caregiving and frustrating attempts to locate appropriate services often leave little time or energy for significant others to pursue their own goals and social relationships (Martone, 2004).

Due to the myriad of factors thought to produce significant stress for couples after TBI, spouses, partners, and family caregivers have often been referred to as “hidden patients” because they are affected by their loved ones’ brain injuries in multiple and long-standing ways that are not easily ameliorated by short-term or simple strategies (Chwalisz, 1996). Unrelenting stress experienced by family caregivers can contribute to more negative views of their loved ones’ brain injury, in part exacerbated by limited or non-existent TBI family long-term services or
supports (Leith et al., 2004; Redpath et al., 2010). Crisp (1993) alludes to this in commenting that: “Not all bias necessarily lies with persons with TBI. Relatives’ perceptions may be distorted when they are experiencing high levels of fatigue or stress” (p. 394).

Ergh, Rapport, Coleman, and Hanks (2002) investigated whether caregiving distress after TBI was moderated by social support. Sixty couples in which one person sustained a TBI were asked to provide information regarding survivors’ awareness of deficits and caregiver functioning through quantitative assessments measuring neurobehavioral and neuropsychological functioning of survivors and caregiver perceived social support. Findings indicated that more significant neurobehavioral and affective problems of survivors were associated with caregiver distress. Caregiver’s perception of received social support was related to their overall feelings of well-being and moderated their feelings of distress. Further, caregivers who reported poor support were thought to potentially have increased levels of distress with time, whereas caregivers with more adequate perceived support were thought to experience a buffering effect from distress (Ergh et al., 2002). The authors recommended longitudinal designs to explore these hypotheses and suggested that caregivers might benefit from ongoing TBI education to alleviate distress. Although this study is illuminating in terms of highlighting a relationship between distress and support and proposing education to address these issues, details of supports and how to procure them were lacking.

2. **Pre-injury Partner Psychological Function and Maladjustment Post-TBI**

Factors associated with family, partner, and survivor stress not directly related to impairments stemming from TBI have been the focus of more recent TBI research (Davis et al., 2009; Godwin et al., 2011; Testa, Malec, Moessner, & Brown, 2006; Vangel, Rapport, & Hanks, 2011). Testa et al. (2006), for instance, explored pre-injury family functioning as affecting
relationship adjustment after TBI. Their contention is that partners with dysfunctional coping and relating styles prior to TBI will be at heightened risk for relationship breakdown following brain injury. The authors compared groups of individuals with mild and moderate-to-severe TBI and groups of people with TBI versus orthopedic injuries and their families on a standardized family functioning measure to assess the level of family adjustment to injury. They also asked families to assess the survivor’s symptoms on a behavioral scale in order to comprehensively collect information on physical, cognitive, behavioral, and emotional symptoms associated with TBI. It should be noted that the circularity of these methods has potential drawbacks because the ways that partners assess injury-related symptoms may be a product of how they are dealing with these issues. As a result, the methods and findings may be questionable. Their results suggested that reports of family functioning distress prior to injury as well as more neurobehavioral problems were correlated with higher rates of impaired family functioning one-year post TBI. They argued for more research that investigates in-depth the ways in which couples relate to each other prior to and following injury, because long-term family dysfunction may pose an increased risk for exacerbated relationship distress following discharge home. Referral for appropriate family intervention and ongoing post-discharge follow-up was recommended.

A recent study investigating predictors of caregiver distress and perceived burden following TBI (Davis et al., 2009) examined spouse and other family caregivers’ pre-existing psychosocial and medical issues by collecting information about caregivers’ medical and psychiatric histories and administering scales and a questionnaire depicting such factors as caregiver coping, perceived social support, and physical and emotional symptoms since their loved ones’ TBI. Results indicated a significant correlation between histories of medical or psychiatric problems and increased levels of post-TBI caregiver distress after accounting for
variances in levels of function of survivors and perceived levels of support. Recommendations included interventions that address both the development of coping strategies for injury-related stressors and broader stress management techniques to assist in ameliorating global distress.

The correlation between caregiver and partner psychological well-being and the life satisfaction of TBI survivors was investigated by Vangel et al. (2011) by administering evaluations at specified time periods. The authors hypothesized that caregivers’ perceptions of social support would directly contribute to survivor well-being. Indeed, the strongest predictor of emotional suffering for persons with TBI was life dissatisfaction of their caregivers. Conversely, the well-being of survivors was most prominently correlated with caregiver perceived level of social support. These findings were valid at follow-up periods as well as initially, suggesting that the interplay between survivor and caregiver is entrenched and needs to be taken into account when developing treatment interventions. Furthermore, it was suggested that interventions that address relationship dynamics in families may be more useful long-term than interventions addressing individual impairments (Vangel et al., 2011).

Although not directly focused on people with TBI, researchers have offered insights into caregiving styles that may explain why some couples seem to fare better than others in times of stress (Feeney & Collins, 2001; Feeney, 2004; Goff et al., 2006; Grau & Doll, 2003). Feeney and Collins (2001) administered questionnaires to 202 couples to assess differences in caregiving styles and factors that mediated caregiving. The researchers found that adults who display low-anxiety and low-avoidance behaviors were secure or supportive and nurturing caregivers; adults who presented with high-anxiety but low-avoidance behaviors were less responsive and more controlling in their caregiving role. Adults who demonstrate both high-anxiety and avoidance behaviors tended to be compulsive and controlling, while individuals with low anxiety but high
avoidance tended to be dismissive and unresponsive to their partner’s needs. Different caregiving styles seemed to engender consequences for partners and for the relationships. Caregivers who were warm and responsive had partners who were secure and reported positive self-esteem. On the contrary, caregivers who were negative, controlling, or intrusive were perceived negatively by the recipients of their caregiving (Feeney, 2004). Feeney (2004) demonstrated that empathy and orientation toward responsiveness were strong predictors of social support caring in intimate relationships.

Secure adults tend to be responsive caregivers and were able to help their partners solve problems. On the other hand, insecure adults tend to be poor caregivers. Unresponsive caregiving, however, is portrayed differently depending upon what type of insecurity an individual demonstrates (Feeney & Collins, 2001; Grau & Doll, 2003). According to Grau and Doll (2003), the quality of attachment styles affects whether partners experience their relationship as equitable or inequitable.

Good caregiving, it seems, constitutes being able to respond to a partner’s needs in times of distress (Feeney & Collins, 2001). Traditional perspectives on caregiving have focused on the person receiving care or on caregiver stress, but views of caregiving as a dyadic, dynamic process are lacking (Feeney & Collins, 2001). Feeney (2004) reported that both partners actually provide and receive care simultaneously and any examination needs to take these contextual aspects of caregiving into consideration (Godwin et al., 2011; Vangel et al., 2011).

These specific caregiving characteristics may be relevant in terms of intimate relationships in targeting specific interventions depending on particular styles. For instance, Feeney and Collins (2001) suggested that in times of distress, caregivers often absorb the majority of responsibility when their stress levels may be high, energy level is low, and as a
result, there are few reserves to provide support to their partner. Since partners may simultaneously share caregiving and receiving, or attachment roles, stressful occurrences may be shared and the relationship is at risk to deteriorate (Grau & Doll, 2003). If TBI researchers and clinicians who are interested in intimacy consider these features, they may be able to glean critical information to help couples address intimacy issues. There has been some speculation that traditional TBI interventions may neglect important characteristics of caregivers, for example, that not all caregivers are equally responsive to their partners’ needs and desires (Feeney & Collins, 2001).

3. **Relationship Stability and Other Temporal Issues**

In a qualitative study examining marital stability two years following TBI, risk factors for unstable marriage or separation included incurring TBI at a younger age, being male, having moderate injury severity, and sustaining TBI from violence (Arango-Lasprilla et al., 2008). Interestingly, another finding indicated that minority status was a factor contributing to more stable relationships, perhaps due to strong cultural family values. Recommendations included conducting further studies to compare perspectives from people of various ethnic or racial backgrounds and that span greater periods of time post TBI to determine if the identified risk factors remain constant across time and diverse backgrounds.

There is a need for additional follow-up or comparison studies to help develop a theoretical basis for further research investigating intimacy and sexuality after TBI. Although studies examining relationship stability 10 or more years after initial injury are rare, they are beginning to emerge in the literature (Gaudet et al., 2001; Hammond et al., 2011; Kreuter et al., 2009; Levack et al., 2010; Mills & Turnbull, 2004; Yivisaker & Fenney, 2001). Kreutzer et al. (2009) compared caregiver well-being one to five years post TBI among a group of spouses,
parents, and other caregivers. They found that distress levels among all caregivers were comparable, but spouses reported depression more often. Higher caregiver distress was associated with TBI survivors who had worse functional status and needed more supervision. Higher stress was also associated with survivors who reported decreased life satisfaction and consumed alcohol excessively. Caregivers reported improved well-being when survivors were either employed or engaged in unpaid vocational roles. It was also reported that emotional distress tended to stay constant over time. Implications of this study underscored the need for long-term support and services for caregivers (Kreutzer et al., 2009). Blais and Boisvert (2007) recommend longitudinal studies with large representative samples of people with TBI. They emphasize that these studies are critical to decide on future strategies and resources needed by people with TBI and their spouses. More specifically, Crisp (1993) postulated that future TBI research needs to focus on survivors’ transitions through various life stages and life events after TBI and should avoid explorations based on a single point in time in order to represent experiences in more depth and more realistically.

A study by Lefebvre, Cloutier, & Levert, (2008) utilized in-depth interviews to explore long-term impact of TBI on survivors and their family and friends 10 years or more after injury. Results revealed that difficulties in coping appear many years post-TBI partially because of lack of post-rehabilitation supports. Half of the participants ended up divorcing or separating and attributed their break-ups to insufficient information and not being prepared for changes in the relationship. As in the other relationship studies, long-term follow-up and TBI education, both clinically and through research dissemination, was noted as critical to the welfare of TBI survivors and their families.
Increased caregiver stress after TBI usually does not fully emerge until at least nine months to two years after initial injury, according to Chwalisz (1996). She proposed a model of perceived caregiver stress that conceptualizes stress and coping as temporally influenced. Chwalisz (1996) proposed that caregivers initially draw upon previous coping abilities and strategies and the support of family and friends, but later are often at a loss because there are too few outside resources to access. Even when resources might exist, access to them or even knowledge of their existence may be limited. Problem-focused coping was found to be negatively associated with perceived stress, suggesting that when the uninjured partners utilized tangible solutions to alleviate stressful situations they experienced less stress. Other factors that contributed to decreased perceived stress included the knowledge that resources were readily available in the community, such as homemaking assistance. Development of in-home training for caregivers following discharge from rehabilitation was also identified as a potentially valuable resource for survivors and families in mitigating their experience of stress (Chwalisz, 1996).

Studies examining relationship or caregiver functioning after TBI have frequently identified grief and stress noted within one month of injury and extending many years later (Brown et al., 2011; Hawthorne, Gruen, & Kaye, 2008; Norup, Siet, & Mortensen, 2010). Until recently, there were few investigations focusing on TBI adjustment longer than 5 to 10 years post-injury, yet the literature advances the notion that relationship challenges increase as time after injury elapses (Katz et al., 2005; Kravetz et al., 1995; Lefebvre et al., 2008).

Very long-term adjustment to TBI, e.g., 10 years and longer, is only now being considered because until now, the public’s lack of exposure to persons with TBI in the community has obscured the fact that TBI is a national health concern with long-term impact
(Kirschner, Mukherjee, Savage, & Brashler, 2003; Linden & Boylan, 2010; Redpath et al., 2010; Selassie et al., 2008). More recent TBI literature reveals long-term consequences for TBI survivors including depression, social isolation, decreased general health and loss of vocational and family roles (Hawthorne et al., 2008). Brown et al. (2011) highlighted the dynamic nature of TBI recovery in their survey study examining quality of life and barriers to community integration for TBI survivors long-term. The authors cite psychiatric difficulties, loneliness, and social withdrawal as the major problems that persist many years after TBI, although there is also evidence that some initially reported problems abate with time (Brown et al., 2011).

Katz et al. (2005) indicated that levels of perceived burden might peak at five to eight years post TBI and then level off after that. The authors proposed that the high rate of divorce after TBI during this time period correlates with caregivers’ realization that their loved ones’ deficits are probably permanent. Additionally, they suggested that marital discord might dissipate after this point because partners learn to adjust in time to their partners’ and their relationship changes. Examining the relationship between length of time post TBI and relationship adjustment is an important area in TBI family research. Interventions may need to be tailored more precisely for specific time periods along the adjustment process if time is consistently identified as a significant factor affecting relationships after TBI.

4. **Summary**

Theories of caregiver burden and stress after TBI are well-known. Contributing factors to stress are the daily challenges that partners confront such as loss of income, increased responsibility, and lack of social supports (Leith et al., 2004; Ergh et al., 2002). Social support perceived by uninjured partners has been shown to reduce the experience of stress (Kreuter et al., 2009), and active problem solving by partners has been examined as a factor in alleviating
challenges, but these findings are inconsistent in more recent literature. Little has been explored from the point of view of survivors regarding factors related to stress or how they conceptualize their partners’ expression of stress. More current research illuminates factors beyond survivor impairments that are associated with increased stress and maladjustment after TBI.

There is an emerging body of literature that points to the influence both partners have on each other’s well-being after TBI (Godwin et al., 2011; Vangel et al., 2011). For instance, uninjured partners’ pre-existing medical and psychosocial issues may also predispose them to experience higher levels of stress, which can impact their ability to support or nurture their relationships or loved ones (Davis et al., 2009; Vangel et al., 2011).

Studies have begun to emerge that suggest intimacy after TBI needs to be explored over time to fully appreciate temporal aspects that influence adjustment and well-being for couples (Gaudet et al., 2001; Levack et al., 2010). Current TBI family literature reveals some beginning strides in identifying key features that affect intimacy and sexuality after TBI. Researchers’ understanding of the significance of temporal issues, for instance, has expanded from Wood and Yurdakul (1997) findings that marital and other personal relationships often deteriorate five to eight years after initial injury to more recent work suggesting that a leveling off and improvement in personal relationships can occur with time (Brown et al., 2011; Jones & Curtin, 2011). Decreased stress has been reported with further time from initial injury (Levack et al., 2010), but again, this has not been examined in any consistent fashion as yet, so it is difficult to make inferences in terms of increased relationship stability. A correlation between survivors’ return to work and partner satisfaction has been suggested (Kreutzer et al., 2009), but this finding is also inconsistent. Studies that identify factors that may lead to good relationship adjustment over time are limited and not based on larger theoretical relationship frameworks.
D. **Intimacy Research**

1. **Major Tenets and Theoretical Frameworks**

   It is commonly understood that intimacy significantly impacts well-being, yet exactly what constitutes intimacy and ways to measure it have challenged both researchers and clinicians (Gaudet et al., 2001; Hook, Gerstein, Detterich, & Gridley, 2003; Lippert & Prager, 2001; Mackey, Diemer, & O’Brien, 2000; Mills & Turnbull, 2004). In an attempt to identify characteristics associated with intimacy, Lippert and Prager (2001) explored working definitions of intimacy among 113 couples through intimacy questionnaires and daily diary entries of the couples’ interactions over the span of one week. Variables such as pleasantness of interactions, disclosing personal information, feeling understood, communicating emotions, and expressing positive feelings about ones’ partner reflected participants’ perceptions of what intimacy meant to them. The authors identified the daily interactions among couples and the multiple types of self-disclosure reported, e.g., personal, private information, emotions, and positive feelings about a partner, as the strongest predictors of satisfying relationships (Lippert & Prager, 2001). Self-disclosure is supported in much of the intimacy research as a prominent characteristic of intimate relationships (Hook et al., 2003; Mackey et al., 2000). Mackey et al. (2000) indicated that feeling safe in disclosing personal information, being able to identify one’s partner as one’s best friend, and believing that the partner is someone one can confide in unconditionally are some of the features that characterize psychological intimacy. Other key features include a sense of equity, verbal sharing of personal thoughts and feelings, fairness in decision-making, and physical contact. In fact, positive communication with one’s intimate partner is believed to be a key feature for the establishment and maintenance of healthy relationships (Mackey et al., 2000).
2. **Gender Differences in Intimacy Literature**

Although gender discourse in the intimacy literature has been well documented (Engel, Olson, & Patrick, 2002; Hook et al., 2003; Lippert & Prager, 2001; Mackey et al., 2000), there is a significant lack of research exploring gender issues from the point of view of people with TBI or their partners. It is generally believed that women associate intimacy with love and affection whereas men tend to view intimacy as synonymous with sexual behavior and physical closeness (Hook et al., 2003; Engel et al., 2002). This dichotomy has been identified as a potential source of conflict that can cause significant relationship discord (Hook et al., 2003). In addition, Lippert and Prager (2001) note that women more readily associate self-disclosure with intimacy experiences than men. Men have been characterized as placing more emphasis on the positivity of an interaction with an intimate partner.

Hook et al. (2003) utilized three intimacy scales to examine differences in perceptions of intimacy among 360 undergraduate students. Women expressed a preference towards tenderness and affection significantly more than the men. Also the female participants reported feeling more confident about themselves regarding their participation and achievements in social, sexual, and intellectual activities as compared to the males. One similarity between the two groups, however, was their reported comfort with both giving and receiving emotional support. The implications of this study are that professionals need to appreciate the different ways in which men and women express intimacy and develop skills to effectively address these variations when counseling couples (Hook et al., 2003).

Mackey et al. (2000) explored the meanings of psychological intimacy through in-depth interviews with 216 heterosexual and same-sex partners from diverse religious, ethnic, racial, and socio-economic backgrounds. Psychological intimacy was defined in this study as feeling
that one could be fully open and honest in discussing personal thoughts and feelings that are not usually shared within other relationships. A critical characteristic correlated with psychological intimacy in this study for all participants was positive communication. In particular, male participants identified proximity and interdependence as the most critical factors of psychological intimacy whereas female participants were more likely to identify openness and mutuality as key concepts. Lesbian partners also tended to want to avoid conflict for fear of being abandoned by their partners early on in their relationships more than heterosexual couples or gay men. However, as lesbian couples became more comfortable in their relationships they reported taking more risks and confronting their partners in order to improve faulty communication. Not surprisingly then, women in same-sex relationships readily indicated that intimate communication was an intensely important characteristic of their relationships more often than heterosexual and men in same-sex relationships (Mackey et al., 2000). In working with lesbian couples in which one partner has a TBI, it may be helpful to understand that their communication style may not necessarily be the same as that of heterosexual couples.

In a study utilizing self-reports and observations to examine the reactions of 79 couples who shared positive versus negative events with each other, Gable, Gonzaga, and Strachman (2006) found that participants felt most understood, validated, and cared for when their partners enthusiastically responded to positive achievements versus when they responded to negative events. A possible explanation for this finding was that when partners share positive events they are sharing and exposing their strengths to each other. When one’s partner validated these strengths, it contributed to one’s self-esteem. Gender distinctions regarding self-disclosure of positive events were observed. Specifically, males’ perceived responsiveness by their partners to positive occurrences predicted relationship well-being, whereas responsiveness to negative
events did not. In contrast, females’ perceptions of their partners’ responsiveness to both positive and negative events predicted relationship well-being in the present. Interestingly though, only responsiveness by their partners to positive disclosures predicted future relationship health for women (Gable et al., 2006). These findings have implications for intervention with TBI couples in that attempts to provide support to one’s partner in response to positive information may be helpful in building up resources that can then help to strengthen their relationships in times of stress or challenge.

3. **Gender Differences in the TBI Literature**

Self-perception of sexuality after TBI was examined for potential differences between male and female survivors (Gaudet et al., 2001). The possibility of sexual disturbance related to a decrease in sexual drive, self-control, confidence, and feelings of sexual attractiveness after injury was explored with 50 people with and 55 without TBI. Participants were administered two questionnaires regarding their perception of their sexuality, behavioral, and emotional symptoms, such as mood swings, depression, irritability, or social withdrawal. Perceptions between men and women with TBI regarding their feelings about their own and their partners’ sexuality were also examined. The respondents with TBI reported less positive feelings about themselves, their relationships, and their sexuality than the respondents without TBI. In addition, in terms of TBI survivors, women reported more positive feelings about their sexuality than men (Gaudet et al., 2001). This was perhaps related to social pressures on men to perform a certain way sexually that became limited or impossible after TBI. The authors note that gaining information from significant partners and professionals would contribute further to our understanding about how sexuality is affected after brain injury. Richer and more in-depth
descriptions of how intimacy issues are perceived by both survivors and partners would help to develop targeted intervention strategies that benefit both partners.

To explore how uninjured spouses regarded their partners’ TBI, Hammond et al. (2011) conducted two separate focus groups with male and female uninjured partners. Focus group responses revealed two primary themes: pulling together and pulling apart, signifying mechanisms partners utilized to cope with dynamic changes in their marital relationships. Some examples of pulling together included partners trying to increase conversations with each other and making an effort to spend more leisure time together. Concepts that incorporated pulling apart had to do with uninjured partners withdrawing physically and emotionally, sometimes as a defensive response to perceiving their injured mates as distancing themselves from them. Female partners had more negative experiences and had more difficulty coping with the changes in their spouses and relationships. They reported more grief regarding the loss of their pre-TBI partner and expressed a desire for their loved ones to change to be more like they were before injury. The female partners tended to withdraw physically and emotionally as a means of coping with their loss. In contrast, the male partners reported more acceptance and less of a sense of loss over their mates’ changes. Potential explanations for the discrepancies between men and women included the fact that men tend to participate in less self-disclosure than women. Further research investigating possible gender differences in coping and ways that treatment could affect the process was recommended. One limitation of this study was that it only explored the uninjured spouses’ perspectives, and thus, a limited understanding of the dynamics of relationships was obtained. In addition, utilizing in-depth interviews might have prompted more complex responses from both groups. Hammond et al. (2011) suggested that there were gender
differences in how uninjured partners perceived their marital adjustment and stability after their spouses sustained TBI.

Sexual role identification and other traditional gender role domains are often altered following TBI. This can pose a significant problem, especially for men because TBI is said to be almost twice as prevalent among men as women, especially in the ages during which they are sexually active (Jones & Curtin, 2011; Schopp, Good, Barker, Mazurek, & Hathaway, 2006). As Schopp et al. (2006) suggest, men’s sexuality was a major life role that directly affected their sense of self, due to societal expectations of masculinity. Sexual dysfunction at all stages has been documented in the literature (Jones & Curtin, 2011; Schopp et al., 2006), including sexual response, desire, arousal, and frequency. Schopp et al. (2006) demonstrated, through a two-year study of 33 men with TBI, that sexual performance declined for a majority of the participants. In addition, overall body image deteriorates and traditional male roles, such as being the primary breadwinner, change in ways that might significantly contribute to men’s perception of their overall effectiveness and attractiveness (Schopp et al., 2006). Their recommendations for therapy include helping male survivors to redefine traditional attitudes about sexuality and intimate relationships and to replace maladaptive views of masculinity with ones associated with self-efficacy and empowerment. Research recommendations include qualitative inquiry exploring men’s coping and adjustment to TBI (Schopp et al., 2006).

Jones and Curtin (2011) conducted semi-structured interviews with eight male survivors in order to explore their sense of their gender identities after TBI. The major finding from the interviews was that masculinity was a dynamic identity component that some of the participants were able to negotiate in order to better reflect their current situations and capabilities. Some respondents had more struggles giving up the socially constructed ideas of masculinity and
expressed more negative life satisfaction. Reformulation of identities was also found to be a
dynamic process that took on different characteristics with time. The authors stressed the
importance of examining experiences over time to describe and understand all of their nuances.
It is also imperative for rehabilitation interventions to avoid following fixed and objective goals
in order to take changes into account that shape people’s needs at particular times. Evaluation
and intervention models need to incorporate reconstruction themes to more readily address the
complexities and dynamic nature of adjustment after TBI. Since self-identity reconstruction for
the male participants was considered to be an important component of successful rehabilitation,
it would be informative to explore whether there is similar application for women survivors or if
this is primarily an issue for men because their traditional breadwinning roles are susceptible to
change after TBI.

Social isolation and emotional functioning issues experienced by women with TBI were
explored in a study conducted by Mukherjee et al. (2003). Case studies involving the personal
experiences of two women who sustained TBI and their psychotherapists were conducted to
explore adjustment issues relevant to women with TBI. One problem identified for women with
TBI is that they are often isolated from mainstream women support groups and social activities,
in addition to intimacy opportunities. Married women with TBI report marital problems
involving feeling sexually unattractive as well as an inability to communicate effectively with
their partners. Feelings of shame, anxiety, hopelessness, and post-traumatic stress symptoms
were common among the women seeking psychotherapy. Recommendations for working with
women TBI survivors included connecting to the disability community to increase social
connections, such as independent living centers or community TBI support groups. Exploring
the loss of previously held senses of self and reframing new identities, including alternative ways
of expressing intimacy, were noted as important dimensions of counseling women with TBI (Mukherjee et al., 2003).

In another study, predictors of continuous marital stability two years after TBI were examined utilizing a retrospective design with a sample of 977 married participants who were at least one to two years post TBI (Arango-Lasprilla et al., 2008). Factors including younger age, being a man with a TBI, sustaining TBI as a result of a violent injury, and having moderate injury severity predicted marital instability. However, identification as an ethnic minority member was associated with greater marriage stability. According to the authors, potential explanations for the moderation factor of ethnicity included strong culturally entrenched family values, role of religion, and feelings of guilt (Arango-Lasprilla et al., 2008).

4. **TBI and Intimacy Theoretical Frameworks**

Family systems theory offers a framework in which to examine how the integrity of one’s relationship is affected as a result of TBI. Family systems theory posits that each person’s behavior in a family or close interpersonal relationship is a product of both individual and family or dyad dynamics (Vangel et al., 2011; Laroi, 2003; Gan, Campbell, Gemeinhardt, & McFadden, 2006). Family systems theory supports the notion that healthy family functioning is directly related to the functioning of each person within that family system (Gan et al., 2006; Laroi, 2003). Considering a family systems framework as related to couples with TBI means appreciating that there is a reciprocal relationship between partners in which the well-being of the partner with TBI impacts the well-being of the uninjured partner and the well-being of the uninjured partner affects the well-being of the partner with TBI.

Optimally, these dynamics produce a balanced and affirming pattern of relationships and communication among each member of a particular family system. Family systems theory
supports the idea that both partners in an intimate relationship create and continuously define each other’s experience through continuous and interpersonal interactions (Godwin et al., 2011). When a traumatic event, such as TBI is experienced by one partner, the established pattern in the relationship is significantly disrupted. A previously harmonious and balanced couple will be better equipped to reinstate balance and organization. Conversely, a partnership that, pre-morbidly, was characterized by conflict, lack of intimacy, and psychological distress of one or both partners will be less able to adapt (Davis et al., 2009; Hammond et al., 2011; Vangel et al., 2011).

A theoretical inquiry into the relationship between trauma and intimacy is instructive in its applicability to TBI relationship research. Since there is a scarcity of research to date directly exploring effects of brain injury on intimate relationships we may benefit from examining trauma theory as it relates to TBI. For example, secondary traumatic stress theory relates to the phenomenon of how the trauma sustained by the primary trauma survivor inherently affects those closest to the survivor as secondary trauma (Goff et al., 2006; Mills & Turnbull, 2004; Shrout, Herman, & Bolger, 2006). According to this framework, stress is described as being communicable or internalized by primary caregivers as secondary symptoms that infuse all aspects of their day-to-day experiences so that they may report feeling as if they actually experienced the trauma themselves (Goff et al., 2006). Being closely connected physically and emotionally to a person who has experienced trauma becomes a chronic stressor to the caregiver and can be as traumatic, or more, for them as for the person who sustained the trauma originally (Goff et al., 2006; Shrout et al., 2006). Similarly, TBI has been likened to a family disease because of the secondary effects it has on family caregivers (Gosling & Oddy, 1999; Gan et al., 2006). Some of the more recent trauma research extends this notion to explore the effects on
individuals experiencing trauma first-hand and those experiencing it as secondary trauma (Goff et al., 2006; Mills & Turnbull, 2004).

Goff et al. (2006) utilized a qualitative design to explore the effects of trauma on intimate relationships of 18 couples (nine men and nine women), in which one of the partners experienced a traumatic event. The average length of the couple’s relationship was seven years. Through in-depth, open-ended interviews, ten themes emerged that reflected the participants’ intimacy experiences and these were similar across survivor and partner groups. Identified themes included communication, cohesion, understanding, sexual problems, relationship distress, support from one’s partner, and relationship resources (Goff et al., 2006). Of note, there was a complex dynamic that existed regarding experiencing both loss and gain. At certain times, there were negative aspects or losses expressed by participants, such as decreased communication or sexual compatibility, and in other instances participants reported feeling close to their partners and experiencing a strong sense of support from each other. This is a very interesting finding because although some couples demonstrated patterns of unresolved conflict or anger there were also many relationship strengths depicted by the participants, such as patience, support, and understanding. However, problems with sexual intimacy were reported even by couples who described their relationships as very positive.

Future research recommendations include additional inquiry focusing on both partners to compare consistency of themes, especially in couples with similar trauma etiologies. In terms of supports and services, there is a need to consider both positive and negative responses when addressing intimacy issues after trauma in order to appreciate the spectrum of responses involved. It is also imperative to reflect on trauma from the perspective of both partners, not as an individual event, in order to understand how themes can manifest in and affect each partner.
and the relationship as a whole. Further examination regarding the possibility of gender differences in responses to trauma is also recommended, especially regarding partner support and relationship resources (Goff et al., 2006).

5. **Theoretical Frameworks of Intimacy to Guide Relationship Intervention after TBI**

Appreciating trauma as a dynamic process affecting intimate partners in both similar and disparate ways is reflected in the theoretical work of Mills and Turnbull (2004) regarding impact of trauma on intimacy. They challenged rehabilitation professionals working with couples experiencing trauma, such as TBI or other life altering events, to conceptualize it within a family systems theory framework (Mills & Turnbull, 2004; Laroi, 2003; Gan et al., 2006; Vangel et al., 2011). This framework, they suggested, situates trauma as being progressive over time, whereby the actual event has far-reaching ramifications for the entire family system if not effectively addressed initially. They proposed multiple possibilities for intimacy dissolution after TBI, including cognitive, neurogenic, structural, and behavioral changes that pose challenges of both a sexual and non-sexual nature to couples. Recommendations for therapeutic intervention included correcting dysfunctional communication patterns within and between partners.

Several strategies have been suggested to address relationship stability after TBI. One of these strategies is understood as a reframing technique (Mills & Turnbull, 2004). Reframing has been described as creating or nurturing personal stories or imagining scenarios in the future in which survivors and partners successfully adjust to relationship changes. There is an emphasis on replacing negative and disempowering images with images that connote strength and hope (Mills & Turnbull, 2004; Crisp, 1993; Nochi, 1998). Strategies such as replacing loss or grief
associations of TBI with positive projections into the future and imagining resilience and overcoming challenges are also suggested (Mills & Turnbull, 2004). In addition, fostering communication that seeks to replace derogatory or dismissive discourse with nurturing and supportive interactions is believed to be a critical quality inherent in healthy relationships and one to facilitate in therapy with couples (Goff et al., 2006; Feeney & Collins, 2001; Mills & Turnbull, 2004; Mackey et al., 2000). This is of particular importance when examining trauma in which communication abilities become disrupted, such as often occurs in TBI (Schopp et al., 2006).

Other frameworks adopting a family systems-type approach apply the theory that affecting well-being of one partner will have positive effects on the other (Gan et al., 2006; Laroi, 2003). For example, coping flexibility has been identified in the TBI literature as a positive strategy adopted by caregivers to alleviate anxiety and facilitate positive interpersonal relationship adaptation (Katz et al., 2005). It is described as a process of trial and error to identify effective ways to manage and alleviate stress. In their study of wives’ coping flexibility and its impact on how their spouses’ TBI affected them, Katz, et al. (2005) demonstrated that perceived spouse burden increases with increased time since TBI only for wives who demonstrated low-coping flexibility. Findings were obtained through two questionnaires focused on relatives’ burden and coping strategies. This research suggests that deleterious effects of time since injury may be buffered by finding ways to cope effectively after injury.

Blais and Boisvert (2007) sought to understand what personal characteristics of both partners were associated with positive psychological adjustment and marital satisfaction after TBI. They administered a variety of questionnaires and surveys to 140 couples who were one to eight years post-TBI. Findings indicated that the personal characteristics associated with
positive adjustment and marital satisfaction included an effective attitude regarding problems, minimal use of avoidance techniques, and partner perception that his or her injured spouse possesses good communication skills. Also, caregiver partners affected the injured partner’s marital satisfaction but injured partners did not affect the caregiver’s marital satisfaction. The researchers recommended interventions that highlighted counseling with a focus on helping couples develop acceptance strategies for permanent changes. It was suggested that enhancing communication between partners should be one of the main targets of couples’ therapy (Blais & Boisvert, 2007).

The trend towards more affirming concepts of couple adjustment after TBI has begun to surface in more recent literature (Vangel et al., 2011; Turner et al., 2011; Godwin et al., 2011). Godwin et al. (2011), for instance, cited positive experiences expressed by partners regarding dynamic changes in their loved ones after TBI. Less negative associations with caregiving included feeling hopeful that things would improve in the future and getting benefits from the caregiving role. The authors recommended ongoing investigation of factors involved in marital quality after TBI. They also urged researchers to provide evidence through rigorous and comprehensive evaluation methods that supported the importance of attending to marriage after TBI as a critical component of overall brain injury rehabilitation (Godwin et al., 2011).

A strength-based perspective of TBI that frames the brain injury as incorporating positive changes as well as loss or compromise has challenged some previous research on burden and relationship disintegration (Crisp, 1993; Nochi, 1997; Nochi, 1998; Mukherjee et al., 2003; Mills & Turnbull, 2004). Strategies such as reframing or transforming identities are challenging traditional perspectives of attributing only tragedy to TBI. As previously mentioned, much of the TBI research literature encapsulates adjustment from a fixed point, thus failing to consider how
time, along with other factors, such as reconstruction of self and one’s relationship, can shape TBI experiences (Barnes, 2003; Crisp, 1993).

In response to the need for more first-hand knowledge of TBI, Crisp (1993) conducted a series of in-depth interviews with 10 people with TBI over a 12-month period to explore their psychosocial adjustment. The purpose of examining adjustment longitudinally was to conceptualize reconstruction of self after TBI as a dynamic process. Different types of psychosocial responses to TBI were discovered that ranged from feeling powerless, struggling to regain one’s pre-injury self, and striving to feel satisfied with one’s altered self, to an embracing of one’s new disability status as positive and empowering. All participants experienced an abrupt life transition as a result of TBI but their reactions varied and were found to fit into one of the typological categories described. The implication for professionals is that a variety of support and resources must be considered and made available to effectively respond to diverse needs and coping styles (Crisp, 1993).

Emerging research that cites positive adjustment after TBI over time are primarily accounts from survivors, not family members, and the methods as well as the factors assessed are inconsistent across studies (Levack et al., 2009; Jones & Curtin, 2011; Saban, Smith, Collins, & Pape, 2011). Levack et al. (2010) undertook a meta-analysis of qualitative inquiry from research spanning 1965 to 2009 in order to examine outcome measures of survivors’ lived experiences after TBI. The authors sought to increase knowledge of measures that would best reflect issues most important to people with TBI. Important themes included reconstruction of self, place in the world, and personhood, but outcome measures related to these themes were not established in the literature. The authors recommended that continued examination of survivor and family perspectives of their experiences is relevant to identify pertinent issues at different periods after
injury and to reveal gaps in how we currently assess outcomes most important to individuals and their loved ones experiencing TBI (Levack et al., 2010).

Rehabilitation researchers are urged to adopt more disability-conscious perspectives that take societal stereotypes into consideration in order to assist people to develop more self-affirming identities: “…Rehabilitation counselors should pay more attention to the third theme not to neglect such societal factors that may influence their clients’ experiences of loss of self” (Nochi, 1998, p. 875). According to Nochi (1998), professionals should assist survivors to construct new, more self-affirming narratives that embody strength and change. Collecting meaningful stories of participants’ transformed realities requires the skill of the interviewer to motivate the interviewees to share their stories. Barnes (2003) emphasized the importance of redefining disability and challenging the dominant research models.

Integrating these strategies within a family systems and secondary trauma theoretical perspective of caregiving and receiving offers a multidimensional perspective and takes into account individual variations of caregiving styles of partners (Mills & Turnbull, 2004; Goff et al., 2006; Nochi, 1998). These dynamics can be very informative in helping couples cope and provide support to each other after TBI.

6. Summary

In general, intimacy research indicates that good communication is a major indicator of positive intimate relationships (Hook et al., 2003; Mackey et al., 2000). Self-disclosure preferences are somewhat varied by gender, with women attaching more importance to emotional self-disclosure than men (Mackey et al., 2000; Hook et al., 2003). Both partners have also been reported to gain the most positive feelings for their relationships when they have an opportunity to both give and receive support (Gable et al., 2006). Interestingly, there is some
evidence that intimate partners attach more positive feelings to their relationships when their partners offer support of positive events versus negative events, perhaps because attending to positive issues contributes to one’s self-esteem (Lippert & Prager, 2001; Gable et al., 2006). However, women, more than men, were reported as more likely to benefit from recognition of both negative and positive events in the short-term but only positive events in the long-run (Gable et al., 2006).

Gender differences in the TBI literature indicate that male survivors more often than female report decreased sense of their own sexuality, and feelings of low self-esteem regarding their masculinity and body image (Gaudet et al., 2001; Jones & Curtain, 2011; Schopp et al., 2006). Hammond et al. (2011) found that female partners more readily reported less positive feelings towards their injured partners as compared to male partners. However, an integration of general intimacy and TBI relationship research is lacking, and therefore factors that address assisting couples after TBI to strengthen their relationships based on intimacy theories is limited.

The application of family systems and trauma theoretical frameworks to TBI and intimacy provides some perspective about how couples might fare and what supports are most likely to help mediate the strain and loss they experience (Goff et al., 2006; Vangel et al., 2011; Laroi, 2003; Godwin et al., 2011; Hook et al., 2003; Gable et al., 2006; Feeney & Collins, 2001; Feeney, 2004). Family systems theory (Laroi, 2003; Gan et al., 2006) proposes that a reciprocal relationship exists between partners and that they each affect the other (Gan et al., 2006). These concepts coupled with the idea that uninjured partners experience trauma along with their loved ones as understood from trauma theory (Goff et al., 2006) broaden the scope of how intimacy after TBI is perceived. As with much of the TBI and relationship research, though, their utility is limited until further research contributes to supporting these concepts.
Literature that addresses life satisfaction of survivors and family members poses potential strategies for improving one’s sense of self or situation after traumatic injury (Mills & Turnbull, 2004; Blais & Boisvert, 2007). The objectives of these strength-based strategies that reconstruct loss by reframing or transforming reality include replacing loss with growth or resilience (Blais & Boisvert, 2007; Godwin et al., 2011; Hammond et al., 2011; Mukherjee et al., 2003; Crisp, 1993; Nochi, 1998; Turner et al., 2011).

These frameworks are promising for altering the ways that partners and survivors perceive themselves and are perceived by others. Utilization of these types of strategies may help replace ideas of pre- and post-TBI selves with newly transformed selves that are not necessarily inferior states as compared to pre-TBI (Hill, 1999; Nochi, 1998). Transformed selves and experiences of loss through others’ assumptions are constructs that would be interesting and important to explore in terms of how they affect the intimate relations of couples after TBI. These concepts have social and cultural implications but have not been previously explored in any depth in the empirical literature.

E. Social Support and Rehabilitation Research

Social support is a consistent theme throughout most of the TBI family literature as an important feature affecting relationship stability after TBI (Wallace et al., 1998; Wallace & Bogner, 2000; Leatham et al., 1996; Ergh et al., 2002). However, supports are often addressed vaguely without a complex conceptualization of the process involved. Thus, a major gap in the literature is the lack of a socio-political perspective regarding TBI supports and service needs. Furthermore, the analysis of support tends to be limited to an examination of support provided by family and friends, which narrows their long-range utility (Chenoweth & Stehlick, 2004; Berkman, Glass, Brissette, & Seeman, 2000; Poortinga, 2006). For example, Wallace et al.
(1998) explored life changes in primary caregivers of persons with TBI one year post-injury. Sixty-one primary caregivers, consisting of spouses, parents, and one friend and sibling, participated in a telephone survey and were given quantitative questionnaires through the mail. Through these data sources, information regarding the amount of social support received by caregivers, caregivers’ perceptions of survivors’ deficits, and their degree of life changes was obtained. The quantity and quality of social supports were more strongly correlated with positive life changes than their loved ones’ injury severity was. Caregivers reported a significant decrease in work and leisure activities, and thus, had fewer opportunities to engage in social relationships. There was also a correlation between the amount of support from family and friends and more positive adjustment overall. The supports mentioned in the study, however, were not described in any depth. The authors recommended development of support services for caregivers of TBI survivors and further investigations using semi-structured interviews and direct observation to better understand the nature of caregivers’ stress and social isolation (Wallace et al., 1998). A limited socio-political context within most rehabilitation research means that TBI is recognized primarily as pathology with little examination of societal treatment of people with disabilities, yet social responses can be the most formidable barriers to community integration after brain injury (Vangel et al., 2011; Struchen et al., 2011; Turner et al., 2011).

1. **Support and TBI Research**

Recommendations for long-term issues after TBI include ongoing supports and interventions aimed at minimizing the negative effects of TBI for survivors and their loved ones (Brown et al., 2011; Hawthorne et al., 2008; Turner et al., 2011; Levack et al., 2009). Unfortunately, supports for family members and TBI survivors frequently diminish once the
immediate crisis of the injury subsides. Rehabilitation and other health-related interventions usually do not extend beyond two years post injury, unless there are secondary health conditions that bring a TBI survivor back into the system again, and the focus is primarily on medical and functional independence versus long-term community living (Turner et al., 2011; Jones & Curtain, 2011; Hawthorne et al., 2008).

Rehabilitation TBI research that focuses on short-term objectives adopts mainly medically or individually oriented goals, such as improving functional independence, instead of life-long support such as accessible transportation, personal relationships, opportunities for advocacy, networking with others, and multicultural awareness training (Brashler, 2004; Levack et al., 2010). It appears that over-emphasis of short-term objectives inevitably creates long-term barriers when the root problems are not addressed from the outset. TBI survivors and their families not only confront long delays and denial of services due to health care professionals’ lack of understanding of the long-term needs of people with TBI (Leith et al., 2004; Martone, 2004), but also tend to internalize other people’s negative ideas about being a person with a brain injury (Nochi, 1997; Hill, 1999; Redpath et al., 2010). This can exacerbate social isolation, social disconnectedness, and feelings of low self-esteem for survivors and family members. Brashler (2004) highlighted the sense of fear and abandonment that family caregivers have reported upon their loved one’s discharge from acute rehabilitation. From the perspective of a social worker she claimed that our current treatment program philosophy and care practices are out of sync with long-term family functioning. One reason for the disjointed priorities is that health care professionals must tailor their interventions and recommendations according to health insurance reimbursement. Families may serendipitously gather assistance from fragmented resources in the community but many report feeling bereft of support and resources (Brashler,
According to Turner et al. (2011), there is both a lack of ongoing services for survivors and their caregivers and also a disjointed system that fails to alert people to the services that do exist. The authors utilized open-ended in-depth interviews to highlight TBI survivors’ and family members’ perspectives on service delivery. A primary problem, according to participants, was the gap in services during the transition from hospital to community. Recommendations from this research included the development of interventions that address various long-term needs (Turner et al., 2011).

Physician Sunil Kothari (2004) claims that health professionals measure quality of life of TBI survivors in terms of the severity of deficits while ignoring other salient contextual factors that would mediate brain injury experiences. The author proposes some ideas that can contribute to more empowering ways to think about people with TBI, such as measuring quality of life longitudinally to allow for changes over time and immersing oneself and colleagues in disability studies literature to broaden one’s ideas of being disabled. Hawthorne et al. (2008) set out to examine self-reported long-term quality of life of TBI. The authors concluded that survivors, as compared to a group of non-injured individuals, reported difficulties with maintaining a job, social isolation, depression, and difficulty maintaining close or intimate relationships 32 months or more post TBI. However, the researchers used standardized quality of life measures rather than gathering open-ended responses from participants that might have contributed further details of their experiences. More studies seeking to capture quality of life challenges after TBI are important in order to provide relevant services and supports over the long-term (Hawthorne et al., 2008).
2. **Support as Passive and “Helping” Within Current Health Care System**

Support as Passive and “Helping” Within Current Health Care System

Survivors and family members have reported being uninformed and unprepared about what to expect, especially after the acute rehabilitation period has ended. Leith et al. (2004) utilized focus groups to explore perceptions of people with TBI and their families regarding TBI services and support. One finding of the study was that health care professionals who work with people with TBI possess limited knowledge and understanding about the complexities of brain injury experiences, and that this prevents TBI survivors and families from obtaining adequate services. As a result, survivors and their partners may end up getting shuffled around the health care system with little guidance or support. On the other hand, educating family members about the long-term aspects of TBI was identified by most of the respondents as helpful in preparing them for the challenges they confronted after their loved ones returned home. The research findings revealed several specific areas of need for long-term adjustment and community integration, such as an additional and longer duration of community and rehabilitation services focused on long-term needs of survivors and their families, TBI education, and training for health care professionals, as well as more opportunities to share one’s first-hand experiences of TBI. This study also revealed that TBI survivors and families desire participation in advocacy and empowerment activities, but that they are not informed about them by medical personnel. It was suggested that professionals need to become more knowledgeable about brain injury and then act as TBI advocates so that TBI survivors and their families can become more empowered to actively participate in TBI research and policy decisions. More research to learn about people’s first-hand experiences after TBI was urged. Similarly, Kreuter et al. (1998) and Ernst et al. (2009) cited a lack of understanding about disability from professionals and the general public as being one of the most limiting factors for people with TBI.
to developing intimate relationships. They observed that having a disability such as TBI may be limiting not only because of actual deficits but also because people tend to avoid intimate relationships with disabled people (Kreuter et al., 1998).

A qualitative inquiry examining satisfaction with social participation of survivors and their caregivers 10 years or more after trauma (Lefebvre et al., 2008) indicated various factors external to the survivors’ capabilities as negatively impacting couples’ relationships. These factors included lack of education about TBI, which left partners unprepared to deal with survivors’ and lack of services, especially long-term. Many partners reported feeling as though they were left to continue the rehabilitation by themselves and lacked the information or access to social integration or other TBI resources that may have helped them cope more satisfactorily. Others reported that families needed to mobilize on a daily basis in order to care for their loved ones, and thus had little time left over to pursue their own lives. More formal long-term TBI educational opportunities and supports for survivors and families were identified as a much needed but currently lacking resource in TBI rehabilitation.

Unfortunately, according to some social support researchers, social supports can be a more charitable or paternalistic presence than an empowering one (Bates & Davis, 2004; Magasi & Hammel, 2004; Berkman et al., 2000; Chenoweth & Stehlik, 2004; Poortinga, 2006). Supports tend to be defined with a focus on helping and socially appropriate skill-building only, and seemed to lack an appreciation for the barriers that people with disabilities have in accessing their communities. Issues like negative societal attitudes, lack of TBI education, and paucity of appropriate long-term community supports are typically not the focus of TBI rehabilitation research (Panko Reis & Baumann, 2004; Mukherjee, Heller, & Alper, 2001; Martone, 2004; Gill, 2004). Rehabilitation approaches to social supports emphasize fitting TBI survivors into existing
potentially disempowering systems and placing blame on the cognitive deficits of survivors if the experience is not successful.

Interventions might more effectively identify salient issues related to relationship difficulties by learning how uninjured partners perceive their intimate relationships. Recent TBI rehabilitation research suggested that significant others are not routinely integrated within their loved ones’ treatment programs (Levack et al., 2009; Leith et al., 2004; Gill, 2004). The lack of consistent inclusion of significant others and family members in inpatient rehabilitation programs has been targeted as leading to less-than-optimal treatment outcomes and limiting adjustment upon discharge home. Levack et al. (2009) conducted open-ended interviews with nine rehabilitation clinicians of various backgrounds who worked with survivors of TBI. The interviews focused on examining how clinicians perceived family members’ involvement in their loved ones’ care and their ideas about how and when to involve families in rehabilitation planning. Results indicated that although health care professionals generally consider family members to be valuable contributors to their loved ones’ rehabilitation, clinicians’ limited family participation in goal-planning in situations where they believed it was not in the best interests of the patients. Thus, goal-planning was deemed to be more patient-centered than family-centered. Clinicians tended to perceive families as potential barriers to survivors’ overall goals, and therefore, did not actively involve them in treatment activities or decisions. Unfortunately, this could have deleterious effects on couples in the long-term because they may lack skills and training to successfully negotiate changes. Not surprisingly, families often report being uninformed and unprepared to be discharged home (Brashler, 2004; Turner et al., 2011; Leith et al., 2004; Kirschner et al., 2003). Recommendations for health care professionals and current goal-planning and rehabilitation-funding approaches need to be reconsidered.
That health care professionals’ biases can affect the provision of services is illustrated by Martone (2004) who wrote as a family member of a TBI survivor. She emphasized the need for professionals to be cognizant that short-term interventions do not always meet the needs of survivors and their families. She was critical of interventions that abruptly ended, leaving TBI survivors and their families with no resources or supports. She argued that home rehabilitation interventions would offer more control and choices to families and survivors so they would not necessarily be restricted by rehabilitation institution protocols.

Ernst et al. (2009) cautioned professionals to consider the dynamic of time when counseling families who may hope for a full recovery for their loved ones in the initial stages after injury. Even though hoping that return to pre-morbid functioning may not be realistic from the point of view of professionals, being sensitive to the stages of coping strategies that families utilize is important in helping them through their adjustment to significant and long-term changes.

3. **Socio-Politically Oriented Social Support**

Recent research has highlighted some key factors that may be important for the creation of substantial support networks for people with TBI and their families. Specifically, research that seeks to examine barriers and facilitators in developing TBI supports in the community and funding for ongoing research reflects a more comprehensive treatment of social support and networks from a larger cultural perspective. Similarly, Panko Reis and Baumann (2004) stressed how important it is for TBI researchers and clinicians to explore the diverse cultures of people with TBI so that more interventions incorporating the diversity of people’s experiences are created. In this vein, Mukherjee et al. (2001) conducted a longitudinal in-depth case study to
examine the multiple contextual issues that mediate people’s experiences with TBI and to describe the social and institutional factors that influenced adjustment to brain injury. The study was informed by a cultural psychological perspective, which views individuals and their environments as interdependent variables. This research perspective also emphasizes that the perspectives of survivors and families are as critical as those of health care practitioners and that “culture is viewed as emergent, dynamic and continually negotiated” (Mukherjee et al., 2001, p. 83). The case study explored the experiences of a male TBI survivor and his sister over a one-year period at various points in time utilizing selected neuropsychological measures and open-ended interviews. The neuropsychological tests assessed cognitive and perceptual functioning of the survivor. Findings indicated that a significant factor influencing this family’s positive adjustment and coping after TBI was the sister’s efforts to be an advocate, because of her brother’s cognitive disabilities. The authors argued that having an advocate is critical to increasing overall quality of life for survivors and families and they implored researchers and practitioners to avoid perceiving impairments from brain injury as the sole cause of adjustment difficulties to the exclusion of wider social-cultural factors. A broader examination of issues that include institutional or attitudinal barriers to effective social supports should be incorporated into research and practice so that improvements can occur in a more substantial and permanent fashion (Mukherjee et al., 2001).

Programs that provide practical as well as emotional support to families after TBI can contribute to couples being less stressed and fatigued, and thereby more likely to be able to nurture their relationship (Gill, 2004). Families can also help advocate for their loved ones when given opportunities to increase their knowledge of available resources or legal aid and advocacy information. Gill (2004) reports: “Families will be in a better position to appreciate their loved
ones with disabilities if they are not exhausted and impoverished. Individuals with disabilities will be able to enjoy family relationships more when they are no longer forced into a dynamic of ‘caregiver versus burden’” (p. 285). Family involvement in various aspects of research can also help to contribute to modifications and accommodations that might improve the survivor’s overall environment to facilitate fullest social inclusion. Families who are included in therapy programs and research agendas might be able to address their social isolation, stress of caregiving without relief, and depression about the loss of the loved ones they knew prior to injury with opportunities for peer support connections to develop. The positive impact for families would be potentially transferred to the TBI survivors as well (Hill, 1999). Gaudet et al. (2001) stressed the importance of conceptualizing “families” as a composition of selected people who support the person with disabilities in respectful and dignified ways. Significant others and other trusted loved ones of TBI survivors may be able to provide important personal information that they both agree is relevant and interesting to share with researchers and other participants.

4. **Theoretical Support Research as Empowering Versus “Helping”**

There has been criticism by some disability advocates that traditional use of support for people with disabilities is largely treated as a predetermined and uni-dimensional provision of services with a lack of regard to how people actually experience and desire to use supports (Magasi & Hammel, 2004; Chenoweth & Stehlik, 2004). It is useful to perceive social support as a complex concept in order to appreciate both the potential and challenges that people with TBI may experience with support. A disability studies perspective of support conceptualizes it as interconnecting resources and relationships. Networks are envisioned as an intricate structure of people and organizations ranging from intimate and ongoing, such as family
and friends, to extended and ongoing or intermittent, such as an independent living organization that an individual or group is engaged in to address social and personal needs (Berkman et al., 2000). Social networks are beneficial to TBI survivors and partners as they can help to provide an environment or opportunities in which members can express a commonality and thereby validate one’s experiences. Close family members or TBI support groups are both examples of social networks that can be beneficial for people with TBI and their significant others.

A concept related to social network is social capital, which encompasses both inclusion and active participation of people within their communities. Social capital has been described as a combination of networks and day-to-day interactions offering people an opportunity to work in collaboration to achieve problem resolution and common goals such as local policies, laws, or practices (Chenoweth & Stehlik, 2004). Its conceptual principles include empowering people to make decisions, establish personal and professional relationships, and have a part in political issues, especially ones that affect people with disabilities. Theoretically, social support networks and social capital comprise a number of complex and interlocking relationships. All of these relationships seem to be necessary in the creation of a buffering effect against traumatic events such as TBI. The social and emotional effects of TBI also significantly affect TBI survivors’ families especially several years post TBI when supports and resources have become scarce or non-existent. Social network and social capital theories indicate that such research will be of only limited value until we incorporate a broader perspective such as facilitating participation in local community groups and organizations or developing reciprocal relationships with others in which support is both given and received (Bates & Davis, 2004; Magasi & Hammel, 2004; Berkman et al., 2000; Chenoweth & Stehlik, 2004; Poortinga, 2006).
Berkman et al. (2000) stressed that through social engagement, individuals are provided opportunities to devise and strengthen meaningful social roles that contribute to a sense of belonging. One social role identified by people as personally fulfilling and satisfying is the role of intimate partner. This role offers one a sense of belonging, identity, and being a valuable person (Berkman et al., 2000). Ongoing in-depth analysis of social support in rehabilitation research is necessary in order to create relevant and long-term interventions for people with TBI so that they can successfully negotiate their important roles, such as intimate or sexual partner. The multiple aspects of social networks must be addressed in order for people to experience the benefits of them. It is also important to gain a deeper understanding of the challenges of implementing such interventions for this population. Although social opportunities are important, they are extremely challenging for people with TBI to access.

Brashler (2004) discussed post-rehabilitation support needs and urged professionals to help advocate for people to continue to receive appropriate and coordinated community services after discharge from acute rehabilitation facilities. Challenges due to scarce funding are factors that need to be addressed. Complex issues that include how one values people with cognitive impairments are critical to address in order to dispel stereotypes that may be influencing third-party payer and health care professionals’ decisions.

A disability studies perspective, with its focus on the social complexities of the disability experience, should encourage the development of opportunities for people with TBI to engage in various productive and meaningful roles so they are afforded the opportunity to learn and practice social skills and develop satisfying social relationships. Emerging research that has adopted a more socio-political cultural framework for people with disabilities is instructive in its focus on the multiple issues of disability across time, cultures and ethnicities. Mukherjee et al.
(2003) and Brashler (2004) urge researchers to incorporate cultural diversity and to appreciate TBI survivors’ and families’ multiple contextual issues and identities because these factors have a significant impact on how individuals experience brain injury.

5. **Sexuality and Intimacy Supports**

Vaughan (2009) viewed occupational therapy as an appropriate discipline to routinely incorporate sexual issues that people with TBI may have because it addresses functional activities. However, the author lamented that in reality, sexuality and intimacy issues are often neglected, mainly because therapists do not feel comfortable bringing sexuality topics up with their patients. Increasing skills and knowledge about intimacy issues may contribute to increasing the support of intimacy training to survivors and their partners. Research that reflects the self-reports of people with TBI regarding intimacy issues (Gaudet et al., 2001) supports the need for increasing these types of supports and implementing further research that includes first-hand experiences of survivors and their families.

Simpson, Anwar, Wilson, and Bertapele (2006) evaluated a two-day sexuality training workshop attended by 74 multidisciplinary rehabilitation and disability professionals. The workshop consisted of eight sessions, each for two days, with a six-month follow-up. The content focused on increasing knowledge, skills, and confidence with sexuality training, with the objective of facilitating sexual health counseling to people with neurological disabilities. Results indicated that workshop participants demonstrated a significant increase in skills regarding sexuality issues that impact people with neurological impairments. Perceived confidence in skills was directly correlated with increased comfort levels in addressing sexual health concerns with clients and families. The authors emphasized that increasing professionals’ knowledge and
skills should be the focus of sexuality training as compared to the more traditional emphasis on attitude change and desensitization of current sexuality training programs (Simpson et al., 2006).

6. **TBI Peer Mentor and Educational Supports**

Peer mentoring has been identified as a potentially promising way to build strong and long-lasting supportive relationships for people with TBI and their families (Panko Reis & Baumann, 2004; Hibbard et al., 2002; Struchen et al., 2011). Hibbard et al. (2002) developed a peer-to-peer support program for community support needs of people with TBI and their families. This “TBI Mentoring Partnership Program (TBI-MPP)” (p. 113) involved five main components consisting of “recruitment and training of individuals to provide peer support, recruitment of individuals and family members in need of peer support, creation of mentoring partnerships, technical assistance, and program evaluation” (p. 114). This community peer-mentoring program was a one-year collaborative project among rehabilitation professionals, people with TBI and their families. The study utilized a participatory action research (PAR) methodology that adopted both qualitative and quantitative methods for data analysis. Peer-support program participants reported positive impacts of peer support on increasing their understanding of TBI, improving their overall quality of life, and giving them strategies to cope with post-TBI depression. There was minimal impact on improving social support from families, friends, and the larger community and there were varying influences on levels of happiness, anger, and anxiety management, communication with professionals, and control over one’s life. Although the results were mixed, peer support intervention programs like this one are promising for people with TBI and their families because of their inclusive methods and far-reaching objectives. Hibbard et al. (2002) stressed the importance of conducting interviews in providing a contextual awareness of the needs of participants and the benefits of the intervention.
from the perspectives of both survivors and their families. In addition, intensive analysis of the peer support intervention included evaluation of project coordinators’ roles, participants’ knowledge and access of community supports and resources, and an understanding that interviews with participants would be conducted periodically over time to gain a more in-depth understanding of the ongoing and changing needs of survivors and family members.

An interdisciplinary team intervention involving an alliance between professionals, clients, and their family members was investigated by Evans, Sherer, Nakase-Richardson, Mani, and Irby (2008). Sixty-nine participants in a control group receiving historically traditional treatment were compared to 35 participants who participated in a post-acute brain injury rehabilitation (PABIR) program. The PABIR program involved ongoing assessments of clients, families, and therapists regarding their perceptions of therapeutic alliance, family intervention that involved TBI education, and nine monthly in-service trainings for therapists. The in-services were designed to help the team improve awareness and knowledge of counseling strategies to build therapeutic alliance. Results indicated that the treatment group had a more favorable functional status, less family discord, more intact family functioning overall, and decreased survivor emotional distress as compared to the control group. Further research on this type of intervention was recommended (Evans et al., 2008).

A social peer-mentoring program for TBI survivors was created and implemented in an effort to increase social participation and activity levels through increased social network size (Struchen et al., 2011). Mentors were TBI survivors, and trained professionals served as facilitators. The effectiveness of this pilot program was evaluated at the end of three months using a variety of quantitative surveys and one assessment that incorporated open-ended interview questions administered to peer mentor program participants. Results revealed that
social activity levels and social network size did not increase significantly for those who participated in the mentoring program. However, participants reported a significantly improved level of perceived social support. Interestingly, information obtained from participants indicated that interventions to improve interpersonal relationships and social participation outcomes are very important. Recommendations for future research included the involvement of peer mentors with and without TBI in order to increase opportunities for survivors to participate in this type of program (Struchen et al., 2011).

7. **Summary**

Historically, our concept of TBI support has been based on views of TBI as needing to be fixed. Our lack of acknowledgement of alternative or positive views of TBI is partly the result of theoretical categorizations of TBI that have been conceptualized without a larger disability or socio-cultural perspective (Kirschner, 2004; Mukherjee, et al., 2003; Panko Reis & Baumann, 2004; Brashler, 2004). Lack of understanding of TBI even among professionals working with this population has been identified as a major deterrent to optimal post-TBI adjustment for survivors and family members (Ernst et al., 2009; Wertheimer et al., 2008). The need for formal TBI education for professionals, survivors, and families is becoming more readily recognized as a critical feature of TBI rehabilitation (Ernst et al., 2009; Redpath et al., 2010; Linden & Boylan, 2010). Broader socio-political conceptualizations of social support for TBI survivors and their partners will contribute to more empowering opportunities to actively participate in communities of one’s choice versus ones recommended by health care professionals or others. Currently, TBI rehabilitation research espouses more of a helping support concept that focuses on short-term issues (Brashler, 2004; Martone, 2004). Unfortunately, these supports fail to contribute to the
development of skills and advocacy necessary for couples to effectively address issues that arise after TBI.

There is emerging research describing more empowering supports. Programs such as peer mentor supports (Struchen et al., 2011) and TBI education and support groups (Hibbard et al., 2002; Evans et al., 2008) are promising in terms of helping couples to develop resources and strengths. Support that has the potential to address not only immediate relationship issues but to inform and change societal conceptions are most useful in the long term to provide both a safety net and building blocks for couples after TBI.

F. **Conclusion**

Although the challenges of social integration after TBI are well-documented (Siebert, Reddy, & Hash, 2002), the impact of TBI on intimacy is less well-known. Research exploring intimate relationships has predominantly focused on married couples who were together prior to TBI (Katz et al., 2005; Kravetz et al., 1995). The specific factors that mediate couples’ experiences, including temporal and other factors, are variable in the literature. For instance, couple adjustment has been correlated with injury severity (Wood & Yurdakul, 1997), amount and quality of social supports (Lefebvre et al., 2008), and coping styles of both partners (Blais & Boisvert, 2007; Godwin et al., 2011). Past studies seeking the perspectives of survivors and family members after TBI reveal that some of the problems they confront include a lack of services, resources, and supports after the rehabilitation phase (Leith et al., 2004; Brashler, 2004; Panko Reis & Baumann, 2004). These factors contribute to families feeling abandoned and left on their own to seek assistance and information. Support and services dwindle away after the initial phase of TBI care (Leith et al., 2004). Although these studies are enlightening, there is
still a lack of understanding of how TBI affects intimacy from the first-hand perspectives of survivors and their intimate partners (Levack et al., 2010).

Some researchers who have adopted a more disability-studies consciousness argue that social support has not been addressed from a socio-political perspective that considers environmental as well as other social issues (Mukherjee et al., 2003; Gill, 2004; Panko Reis & Baumann, 2004). This may be detrimental to long-term adjustment because people with TBI are challenged to establish or enter into social groups or networks that are not physically or socially geared towards accommodating their needs. Establishing TBI supports may be thwarted by deep-seated assumptions and misconceptions about people with TBI even among those who have professional experience with TBI survivors (Redpath et al., 2010; Ernst et al., 2009). As a result, survivors and families often end up with a lack of accurate information, they may internalize professionals’ low expectations, and intimacy and sexuality issues are rarely or incompletely addressed (Redpath et al., 2010; Gaudet et al., 2001).

Intimate interpersonal relationships after TBI have also not been critically examined within the context of intimacy theoretical frameworks that might illuminate how TBI impacts the process (Gaudet et al., 2001; Vangel et al., 2011; Hammond et al., 2011). There is an appreciation that TBI affects the entire family (Gosling & Oddy, 1999; Gan et al., 2006), but the reciprocity between both partners and how this ultimately shapes their relationship is not currently translated into how we theorize interpersonal adjustment after TBI (Anderson & Kitchin, 2000; Mills & Turnbull, 2004; Godwin et al., 2011). In addition, intimacy in TBI research has generally been explored at a single point in time (Blais & Boisvert, 2005) and with a focus on the traumatic event itself as if other factors, such as partner pre-morbid coping styles or social supports, do not affect relationship integrity (Goff et al., 2006; Davis et al., 2009; Leith et
Subsequently, erroneous conclusions may suggest that intimate relationships after TBI inevitably deteriorate (Aloni et al., 1999). However, there is emerging evidence that uninjured partners’ pre-existing emotional and psychosocial coping skills directly correlate with survivor well-being after TBI. These findings offer insights about potential factors other than those directly related to impairment that may affect long-term adjustment for couples (Davis et al., 2009; Godwin et al., 2011; Vangel et al., 2011; Testa et al., 2006).

More current literature supports the notion of positive adjustment for couples (Godwin et al., 2011; Hammond et al., 2011; Jones & Curtain, 2011) and the application of techniques such as reframing of reality to include acceptance and moving on from TBI experiences (Mukherjee et al., 2003; Crisp, 1993; Nochi, 1998). With the emergence of expanded and more sophisticated perspectives regarding relationships and TBI, it is critical to re-assess our current TBI programs, policies, and research agendas and provide the necessary elements to address the complexities and contextual factors of intimate relationships and TBI (Sample & Langlois, 2005; Cope, Mayer, & Cervelli, 2005; Turner et al., 2011; Redpath et al., 2010). Evidence-based research illuminating what features are most important to include in the post-acute continuum of TBI programs for effective long-term coping after TBI are called for (Heinemann, 2007; Turner et al., 2011; Levack et al., 2010; Struchen et al., 2011; Godwin et al., 2011). Interventions focusing on peer mentoring and training to increase social support networks for survivors have also been proposed (Hibbard et al., 2002; Panko Reis & Baumann, 2004; Struchen et al., 2011).

Incorporation of theoretical frameworks of intimacy relevant to TBI and interpersonal relationships may help shed light on how TBI affects intimate relationships (Gaudet et al., 2001; Simpson et al., 2006; Goff et al., 2006). For instance, many of the tenets of intimacy theories, such as the importance of self-disclosure and communication, may help identify aspects of
relationships that might be adversely affected when one’s partner sustains a TBI, and therefore, might be amenable to targeted interventions to bolster communication between partners (Hook et al., 2003; Feeney & Collins, 2001; Goff et al., 2006; Mackey et al., 2000).

Relationship research in the context of TBI will benefit from conceptualizing intimacy after TBI as a dynamic process that potentially improves over time (Vangel et al., 2011; Hammond et al., 2011). Developing a more comprehensive understanding of the broader intimacy research literature will be instructive in increasing our knowledge of what factors challenge or support intimacy, in general, and after TBI, more specifically. This information will contribute to more relevant and inclusive interventions and supports for couples after TBI.
III. RESEARCH PROBLEM

A. Statement of the Problem

Research on intimacy from the perspectives of traumatic brain injury survivors and their uninjured partners is relatively limited. There are even fewer accounts by couples from diverse ethnic or cultural backgrounds, unmarried couples, or same-sex partnerships (Godwin et al., 2011; Arango-Lasprilla et al., 2008). Many notions of relationship integrity after TBI are derived from studies using quantitative measures of marital stress, strain, and caregiver burden (Hammond et al., 2011). These methods are not necessarily equipped to identify potentially positive aspects of relationships that allow partnerships to endure after injury (Levack et al., 2010). Typically, these studies focus on relationship disintegration after TBI that is attributed to the survivor’s impairments. Thus, relationship stability is a significantly understudied aspect of social adaptation after TBI (Kreuter, Sullivan, Dhallof, & Siosteen, 1998; Godwin et al., 2011; Hammond et al., 2011).

A major gap in the literature to date is that the concept of positive adjustment after TBI has not been examined in terms of intimate relationships. Although examination of positive adjustment for couples after TBI is minimal, there has been some research focusing on constructs beyond relationship strain and fragility, such as reframing (Nochi, 1998; Hill, 1999; Mills & Turnbull, 2004) and positive coping (Blais & Boisvert, 2007; Godwin et al., 2011), that have the potential to reflect the dynamic nature of intimacy after TBI as well as the resilience of partners (Perlesz, Kinsella, & Crowe, 1999; Hammond et al., 2011; Brown et al., 2011). Further, studies that extend beyond amelioration of individual impairments to bolstering relationship quality and stability will contribute to furthering our knowledge about what factors are important in
supporting long-term relationship strength for couples (Levack et al., 2010; Hammond et al., 2011; Godwin et al., 2011).

Relationship research in the context of TBI is characterized by a lack of consistency regarding how and when personal relationships might be affected after the injury. Most examinations focus on static points that fail to reflect how relationship challenges or the process of adjustment may change over time (Brown et al., 2010). In addition, too few narrative accounts exist describing how TBI affects one’s sense of identity as an intimate or sexual being (Crisp, 1993; Ylvisaker & Feeney, 2001; Kreuter et al., 1998).

Existing TBI relationship research is not informed by key findings gleaned from intimacy and trauma theoretical research (Gable et al., 2006; Hook et al., 2003; Goff et al., 2006), and this limits our understanding of how TBI affects intimacy. Some of these findings indicate that there are self-disclosure preferences between genders (Mackey et al., 2000; Hook et al., 2003), both partners seem to benefit from receiving and giving support to each other (Gable et al., 2006), and there is a reciprocal dynamic between intimate partners that ultimately affects the well-being of their relationship (Laroì, 2003; Gan et al., 2006; Vangel et al., 2011). Also, caregiving partners have been found to experience trauma (Goff et al., 2006) symptoms just as survivors do, and both partners react and adjust their behaviors accordingly. These dynamics need to be addressed by rehabilitation specialists if relationship interventions are to be effective for both partners. Recent TBI relationship research has also suggested a connection between the caregiver’s pre-injury psychological well-being and intimate relationship adjustment (Davis et al., 2009; Vangel et al., 2011). More inquiries that link intimacy, trauma, and rehabilitation literature will contribute to a more sophisticated understanding of how couples cope and what intervention approaches will be most effective.
Lastly, the treatment of social supports in TBI and relationship research lacks socio-political rigor, which ultimately limits the utility of this research as a tool to analyze relationship integrity after TBI (Panko Reis & Baumann, 2004; Mukherjee et al., 2003; Brashler, 2004). Issues such as discriminatory societal attitudes, lack of TBI education, and paucity of appropriate long-term community supports for couples are typically not the focus of TBI family research (Panko Reis & Baumann, 2004; Martone, 2004). The implications for people with TBI and their partners are that the quality and quantity of TBI interventions in the community will be limited if social factors, like the difficulty establishing or maintaining supportive relationships or access to supports, are not adequately addressed.

Critical aspects of interventions, such as brain injury education, support groups, and peer mentoring programs, are identified in some of the more current rehabilitation research as potentially promising ways to build strong and long-lasting supportive network relationships for people with TBI and their families (Panko Reis & Baumann, 2004; Leith et al., 2004; Hibbard et al., 2002; Struchen et al., 2011). Exploring effective types of supports and how they can best be implemented may help couples buffer the challenges they experience after TBI.

B. **Purpose of Study**

The purpose of this study was to explore how the experience of TBI affects intimate relationships, feelings of intimacy, and one’s self-identity as a sexual or intimate partner from the perspectives of both the survivor and uninjured partner. The concepts of role and relationship changes and stability were examined as well. Facilitators and barriers to intimacy were examined, including social environmental factors. The ultimate goal of the study was to inform support services targeted to strengthen intimate relationships after TBI.
The primary approach was to interview survivors and partners about the issues they believed were important. Among other questions, participants were asked to define what intimacy meant to them, what factors were salient in maintaining intimate relationships, what barriers they had encountered, what actions or ideas had helped or would help, and how they saw themselves as intimate partners in the context of the TBI experience. The secondary focus was to explore how participants could feel empowered to have the kind of intimate relationship and identity they wanted and what factors influenced this process.

This research was informed by a social model of disability in which the challenges of people with disabilities are interpreted as determined by social, cultural, policy-based, and economic factors interacting with functional or bodily difference (Tate & Pledger, 2003). A socio-political perspective facilitated a view of TBI as a dynamic process over time, encompassing potential loss and reconstruction of intimacy following brain injury in the context of social relations. Because this study was not directed by any predetermined set of assumptions, a broad approach was adopted to understand the lived experiences of the couples in the context of TBI and intimate relationships.

The intention in gathering this information is to help inform researchers, clinicians, and TBI advocates to develop relevant programs and services to address the gaps regarding intimacy and TBI. For the purpose of this study, intimacy is defined as being involved in an interpersonal and/or sexual relationship with another person in which positive emotional connections and a commitment has been established (Timmerman, 1991).

C. **Conceptual Frameworks**

Every aspect of this research was informed by a social model of disability that sought to illuminate the issues of intimacy following TBI in terms of complex interactions of physical,
psychosocial, emotional, and environmental factors that shape individuals’ disability experiences. This perspective challenges more traditional or medically oriented models that theorize disability as a static, inferior “abnormal” state of being in need of “fixing” or “curing.” Anderson and Kitchin (2000) characterize a social perspective of disability as recognizing disabled people as a “…heterogeneous population, and that the majority of daily difficulties faced by disabled people are caused by society failing to accept disabled people for who they are and failing to provide adequate services” (p. 1164). Shakespeare et al. (1996) proposes that disabled people encounter barriers to sexuality and intimacy because of prejudicial societal attitudes rather than any bodily impairment.

First, this study sought to attend to the numerous social, emotional, environmental, and physical factors of TBI related to intimacy in order to more comprehensively understand how couples negotiate their personal relationships amidst both personal and social issues. This approach affirms the importance of both physical and social/environmental factors. As Shakespeare et al. (1996) stated regarding the utility of conceptualizing disability models as an embodiment of social, environmental, political and physical factors:

We cannot ignore the role of impairment and the body in our lives. A social constructionist approach that loses contact with the physical does us no favours. I think we have to have a position that recognizes difference, and limitation, and the very real problems, which disabled people may have with their bodies and their lack of function. (p. 162)

More recently, disability scholars have recommended a deeper conceptualization of disability that acknowledges the multiple, dynamic, and universal nature of disability. As Stolzfus and Schumm (2011) articulate:

Increasingly, disability theorists tend to argue against essentializing disability and for recognizing disability as fluid and heterogeneous…The multiplicities of disability are increasingly moving disability theorists and activists to organize for a world that is more
accessible to all, rather than for generalized assertions about isolated individuals or some
generalized disabled group identity. (p. 6)

Secondly, in its most basic form, this study sought to describe something not well known or
understood—the respondents’ “lived experiences” of intimacy and TBI. For this reason, this
study was inspired by aspects of a phenomenological theoretical framework. A
phenomenological design is rooted in the belief that gaining first-hand knowledge of issues, or
phenomena, is the most logical way of understanding something in a deeper, more meaningful
way (Patton, 2002; Padilla, 2003). Muenchberger, Kendall, and Neal (2008) describe a
phenomenological approach as exploring the meanings of each person’s experiences to construct
a framework of understanding. Phenomenological inquiry, according to Padilla (2003) is a
process that enables the researcher to discover the phenomenon in question from direct contact
with participants. In addition, a phenomenological perspective is also appropriate for
illuminating something that is little known or that has previously received limited attention, such
as intimacy after TBI (Wilding & Whiteford, 2005). Framing this study within a
phenomenological perspective allowed the consideration of TBI as a dynamic process over time
that appreciates both the potential of loss and reconstruction of intimacy after brain injury.

A third conceptual framework guiding this study was a family systems model that
situates life events as affecting all members of a family. Simply described, family systems theory
posits that when something affects one person, the other person or people close to that individual
are also affected (Laroi, 2003; Gan et al., 2006; Goff et al., 2006; Rosenthal & Young, 1988).
Some key tenets of family systems theory that are directly applicable to people with TBI and
their partners include the principle that all people within a system are connected to each other
psychologically and behaviorally, and these connections develop over the course of the lifetime
of the family. In addition, family systems theory proposes that a change in behavior or a significant life event affecting one member affects change for all members of that system (Rosenthal & Young, 1998). Laroi (2003) supports the relevance of applying a family systems approach to brain injury intervention based on the assumption that each family has a certain structure or organization in response to how the personalities of each member of the family affect one another. The family system can act as a source of strength or a stress buffer to persons with TBI and their significant family member or members. Therefore, interventions directed at members of a family system are considered more effective than those directed only to the TBI survivor (Vangel et al., 2011; Laroi, 2003).

In this study, the family system was conceptualized as the partnership between survivor and significant other. This idea resonates with the idea put forth by Vangel et al. (2011), which described a reciprocal relationship whereby the well-being of the TBI survivor affected the well-being of a family member, and conversely, the well-being of a family member affected the well-being of the survivor.

A related framework to family systems, secondary trauma theory, was also helpful to understand the effects on both partners experiencing TBI. Secondary trauma has been conceptualized as a process by which people closely emotionally connected to each other experience trauma symptoms worthy of changing the basic core of an intimate relationship (Goff et al., 2006). It has been demonstrated that sexual problems and reduced intimacy are reported by trauma couples even if the trauma was not sexual in nature and that such problems can occur in conjunction with descriptions of positive relationships (Goff et al., 2006). In addition, trauma couples have directly associated open communication with more positive adjustment. These
findings are relevant to the current study and shed light on how survivors and partners coped and maintained intimacy after TBI.

Lastly, social support theories were informative in understanding the ways in which support networks impact relationship integrity following TBI. Key social support concepts situated within a disability studies perspective were applicable to this study. These included the proposed connection between uninjured partners’ perceived satisfaction with social supports and their psychological well-being as well as positive outcomes for survivors (Vangel et al., 2011; Ergh et al., 2002). Vangel et al. (2011) and Ergh et al. (2002) reported a direct relationship between perceived social support of uninjured caregivers and survivors’ positive adjustment.

Horner, Selassie, Lineberry, Ferguson, and Labbate (2008) suggest a link between low levels of survivors’ perceived quality of social support and reduced overall health-related quality of life.

Social support has also been theorized as a multidirectional and dynamic process involving disabled people being recipients as well as providers of support. Also, the ways that support is used and experienced by people with disabilities may have more relevance than the types of support (Magasi & Hammel, 2004). These ideas challenge more traditional notions of support as a passive initiative and one where health professionals decide on the “appropriate” supports to provide.

Chenoweth and Stehlik (2004) differentiated between support that is derived from one’s personal sphere of family and friends and support that is obtained by participation in multiple networks involving one’s broader community of neighbors, co-workers, and other domains in society. One of the difficulties for people with disabilities and their immediate caregivers is not being able to access broader support networks and, thus, the effect is often social isolation that further erodes the ability to develop supports: “…Being socially isolated means there is very
limited access to external supports; consequently, individuals increasingly rely on internal resources (from within their own family) to meet those needs” (Chenoweth & Stehlik, 2004, p. 67).

The lack of or inaccessibility of supports reported by survivors and their partners is prevalent in more current TBI rehabilitation literature and has been correlated to stress and breakdown of intimacy for couples (Turner et al., 2011; Leith et al., 2004; Chenoweth & Stehlik, 2004). It seems prudent to draw on the described social support models in an effort to address barriers to inclusion and to facilitate social connections. For example, social support interventions proposed by Hibbard et al. (2002) and Struchen et al. (2011) offer constructive examples of support networks that have the potential to significantly increase social interactions and relationships for survivors.

D. **Research Questions**

This study posed the following primary research questions:

1. How does the experience of TBI affect intimate relationships of TBI survivors and their significant others?

2. What does intimacy mean to each individual in the aftermath of TBI?

3. What factors lead to positive or negative relationship outcomes? What are the barriers or facilitators or supports that make a difference in the experience of intimacy?

4. How do survivors’ and uninjured partners’ experiences compare and contrast with each other?
Secondary research questions were the following:

5. How is the experience of the intimate relationship stable or changing for both partners, and what factors contribute to that stability or change?

6. How is identity as an intimate partner after TBI affected for survivors and partners?

7. How do social reactions from significant others and family members, acquaintances, professionals, and media images affect intimacy experiences after TBI?

8. What recommendations do survivors and partners suggest for improved clinical and community supports that are helpful to their adjustment process?

E. **Summary**

An exploratory qualitative study was undertaken to discern an in-depth understanding of how TBI survivors and their partners experience intimacy. The major premise that frames this study is that TBI must be considered in relation to an individual’s complex life experiences and in social context.

Issues of intimacy and TBI cannot be fully appreciated without taking one’s total life experiences into consideration. Previous studies on marital relationships and TBI generally fail to do this. First-hand perspectives obtained at different stages after TBI from both survivors and their partners added depth and relevance to this study. The ultimate purpose was to develop recommendations for improved supports and suggestions for follow-up research to identify potential supportive community resources to foster intimacy after TBI.
IV. METHODS

A. Introduction

This chapter details the methods used to explore intimacy and traumatic brain injury (TBI) for a group of survivors and their significant others. Section B outlines the research design, including a brief description of the researcher’s initial exposure to the field. Section C focuses on issues of sampling, including: a) sampling strategies, b) recruitment and consent, d) description of the participants, and e) confidentiality. Section D describes the methods of data collection, including initial qualitative interviews, follow-up interviews, and focus groups. In section E, processes and procedures for data management and analysis are outlined, including: a) data management, transcripts, and field notes, b) data analysis, and c) the collaboration between researcher and analysis auditor used to increase trustworthiness and verification of study findings.

B. Research Design

This two-year qualitative phenomenological (i.e., experience-focused) research study conducted in Chicago, Illinois explored intimacy and traumatic brain injury (TBI) from the perspectives of individuals with direct experience of the issues. As previously mentioned, most explanations of intimacy after TBI have been based in a medical framework that views TBI in terms of impairments and loss (Liss & Willer, 1990). This view of TBI has fostered quantitative research approaches that usually obtain information through pre-formed questionnaires or surveys (Hammond et al., 2011). Because this approach has failed to advance our knowledge of the issues within a broader social context, such as the influence of stereotypes about TBI on intimacy problems, this study sought information beyond a focus on deficit and burden of care. As this study was concerned with capturing and thoroughly describing how participants
experienced their intimate relationships, it was compatible with the values of phenomenological inquiry, which seeks to make sense of and interpret lived experiences (Patton, 2002; Speziale & Carpenter, 2007, Taylor & Bogdan, 1998). Patton (2002) describes the process as “…how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others” (p. 104).

This project sought to privilege the views, experiences, and voices of the stakeholders who often have little opportunity to influence research. In this respect, this work reflected elements of emancipatory research (Priestly, 2003; Barnes, 2003). One of the core principles of emancipatory research, as defined by Priestley (2003), underscores the basic tenets of this study: “…the ability to give voice to the personal whilst endeavoring to collectivise the commonality of disabling experiences and barriers; and the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people” (p. 90). An underlying objective of this study was to understand how intimate partners experiencing TBI could be helped by asking them how the health care system could support them. Changing the lives of disabled people both practically and politically, claims Anderson & Kitchin (2000), is a key factor delineating research as emancipatory in nature.

The use of multiple qualitative methods was accomplished through initial interviews, follow-up interviews at six months, and exit focus groups for both survivors and their significant partners. These methods were selected in order to gather contextually rich reports of first-hand perspectives of intimacy. This approach also facilitated meaningful exploration of participants’ experiences within the context of multiple variables, such as relationship length, relationship stability, available social supports, gender issues, or whether TBI occurred prior to or following the establishment of the relationship.
Qualitative methods are generally viewed as useful when a primary research goal is to increase understanding of the meanings people make of their “lived” experiences (Wilding & Whiteford, 2005). Qualitative rather than quantitative methods are suited to questions aimed at increasing understanding of a phenomenon from particular individuals’ or groups’ perspectives without necessarily generalizing beyond the research (Patton, 2002). As Patton (1999) states: “Keeping findings in context is a cardinal principle of qualitative analysis” (p. 1198).

Qualitative inquiry has the unique capacity to reveal intimacy and relationship issues in a complex and deep way (Levack et al., 2010). For instance, previous research hypothesized that uninjured partners’ levels of stress and burden, coping flexibility, and role incompatibility would affect the integrity of intimate relationships after TBI (Leatham et al., 1996; Katz et al., 2005; Liss & Willer, 1990). Studies focusing on these issues that incorporate qualitative methods contribute illuminating contextual details about the experiences for both partners in the adjustment process after TBI. Gaining first-hand perspectives of survivors and their intimate partners (Lefebvre et al. 2008; Hammond et al., 2011; Levack et al., 2010; Turner et al., 2011) can yield essential information about long-term service and research needs.

This study was unique in its collection of experiential data from both the individual with TBI and his or her intimate partner, and in the inclusion of intimate couples that were diverse with respect to marital, racial and ethnic status, and sexual orientation. New ways to understand intimacy-related phenomena through participants’ vantage points and relevant social context contributed more dimension to how we currently understand TBI and intimacy. According to Huberman (1994), qualitative interviews and observations are thought to best capture complex experience because of their capacity to facilitate in-depth, open-ended inquiry of the phenomena. Interview and focus group questions in this study encouraged participants to share what was
important to them. These methodological choices are supported by Anderson & Kitchin (2000) who describes the views of persons with disabilities in his study regarding the merits of qualitative interviewing in disability research: “…there was strong support for qualitative methods of research, particularly interviews because they allow respondents to express and contextualize their true feelings, rather than having them pigeon-holed into boxes with no or little opportunity for contextual explanation.” (p. 43).

The research topic, design, and interview questions were developed by the principal investigator (PI), and the research was conducted by her with funding through the Rehabilitation Research and Training Center on Community Integration of People with TBI (RRTC) at The Institute of Rehabilitation and Research in Houston, Texas (National Institute on Disability and Rehabilitation Research grant: H133B031117). The original research study took place in the Chicago area and involved 13 couples. It was replicated at the Houston site with six additional couples. However, only the original study conducted by the principal investigator will be reported here.

C. **Site Selection and Recruitment Plan**

Recruitment strategies included mass distribution of research announcements, targeted recruitment through professional and advocate liaisons, presentations to TBI groups, and word-of-mouth “snowball” recruitment. The majority of the participants were recruited from two major health facilities in the Chicago area, including clients who participated in day rehabilitation centers. These sites were selected because of the large number of people with TBI who are seen regularly throughout the rehabilitation continuum starting at the acute rehabilitation inpatient level. In addition, the clients seen in the day rehabilitation centers generally represent people from diverse ethnic and racial backgrounds. Furthermore, the principal investigator was
formerly employed as an occupational therapist at one of the rehabilitation facilities and was able to draw on her professional contacts to help circulate information about the study to potential participants. The PI had had no prior contact with the participants in the study except for one TBI survivor whom the PI met in the physical rehabilitation setting when serving as a substitute for the individual’s primary occupational therapist for one individual session. The PI had not had any further clinical contact with this individual for over a year. Because of the importance of separating clinical services from research activities, the PI made a particular effort with this participant to ensure that she understood that this was a research study with no clinical consequences or benefits and that participation was voluntary. The participant demonstrated a clear understanding of this distinction in her responses to questions about the purpose of the study during the consent process.

Announcements about the study were sent to local TBI support groups and community disability organizations, such as TBI “clubs” and Independent Living Centers with follow-up phone calls to discuss the research further. Representatives of these organizations distributed the study announcement through their communication networks and also assisted in “snowball” recruitment by personally contacting individuals they thought would be interested. These sites were thought to provide a potential group of people from diverse socioeconomic, racial, and ethnic backgrounds. The aim of snowball sampling is to rely on networking between people to identify key informants (Patton, 2002).

It was difficult to recruit participants through merely posting announcements because of the sensitive topic of the research and the need for both partners to be involved. Some individuals who described themselves as doing very well post-TBI said they would like to be in the study and acknowledged the importance of the topic but opted not to enroll because they
feared revisiting experiences that might be too painful and stressful for them or for their partners. They seemed to feel that focusing on past difficulties could upset some of their current hard-won emotional equilibrium. In other cases, one member of the couple wished to be in the study, but the partner either could not or did not wish to participate. Liaisons from post-acute TBI centers helped with more targeted recruitment. They spread the word about the study to potential participants who they believed would be willing to share their experiences. This was very helpful and resulted in many connections. The PI and her advisor also presented information about the study in person at TBI support groups. This personal outreach was also successful in generating volunteers who helped provide initial feedback about the research topic and research questions. This sampling approach is consistent with purposeful sampling standards prevalent in qualitative research, in which participants are chosen on the basis of the experience and information that they can contribute to the research question rather than being selected through representative or randomized methods (Patton, 2002).

D. Participants

1. Sample Size

A purposeful sampling design strategy was chosen for this study because the ultimate objective was to increase our understanding of intimacy and TBI from a group of people who could provide rich first-hand details of their experiences (Sandelowski, 2000; Patton, 1999; Speziale & Carpenter, 2007). Sandelowski (2000) refers to this sampling process as seeking “cases deemed information rich” (p. 338).

For the purposes of this study, a small participant group was desired in order to be able to explore topics in depth and take time to understand and follow-up on participants’ perspectives.
of the phenomenon. However, the sample needed to be large enough to capture critical dimensions of the issues. Past in-depth qualitative TBI studies have used sample sizes ranging from three or four (Glover, 2003; Levack et al., 2010) to 18 (Goff et al., 2006; Gosling & Oddy, 1999). To allow for a balance between sample diversity and the need to limit the number of interviews to a manageable number for in-depth exploration, the recruitment target in this study was set at 12 couples (24 individuals). This target was subsequently expanded to 13 couples in order to recruit a same-sex couple. Patton (2002) warns about adhering to the research purpose when addressing sampling details: “The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size” (Patton, 2002, p. 245).

Because this was an open exploration of theoretically interesting relationships designed to reflect the viewpoints of a broad representation of people with TBI, e.g., in terms of age, gender, injury severity, duration of relationship, ethnic and racial backgrounds, and time elapsed since injury, a maximum variation sampling method was also utilized. According to Sandelowski (2000), maximum variation sampling “allows researchers to explore the common and unique manifestations of a target phenomenon across a broad range of phenomenally and/or demographically varied cases…” (p. 338) and is useful in describing cases that may have unique or underrepresented variables, such as being gay or from an ethnic minority, as was relevant with the participants of this study.

The range of variables in the sample included such factors as ethnic and racial diversity and gender differences in TBI survivors in order to further examine gender issues in intimacy after TBI. A number of couples whose union preceded the injury was sought in order to explore
factors that contribute to relationships that weather the acquisition of the TBI. In addition, there was an interest in including people who have had relationships that have lasted 10 years or longer so that the dynamics of relationship longevity after TBI could be explored. Because the relationship experiences of TBI survivors from ethnic, racial, or sexual-identity minority groups have been under-investigated, there was an attempt to have at least 25% of the sample composed of survivors from these underrepresented groups. This target was achieved.

2. **Participation Criteria**

Inclusion criteria for participants included involvement in an intimate relationship; age 21 years or greater; medical diagnosis of TBI for one member of the couple occurring six months or more before participation; and adequate comprehension, communication skills, and appropriate social behavior to participate in interviews and focus groups. Traumatic brain injury (TBI) is defined in this study as “An alteration in brain function, or other evidence of brain pathology, caused by an external force” (Brain Injury Association of America (BIAA), 2012).

3. **Participant Demographics**

Demographic characteristics for the sample are shown in Table I. Thirteen couples (26 individuals) from the Chicago area were enrolled in the study. Participants were diverse in age, ranging from 23 to 66 years. White, African American, and Latino individuals were represented in the sample. Except for one lesbian (LGBT) couple, the couples were heterosexual. Nine of the 13 couples were married, with the length of time in the relationship ranging from 6 months to 36 years. Four of the couples had begun their relationship after the TBI. Eight of the couples had children between them, and two couples had children from previous relationships. The mean length of time post injury for all the participants was 5.69 years. The median was three years.
TABLE I: DEMOGRAPHICS OF PARTICIPANTS WITH TBI AND PARTNERS

<table>
<thead>
<tr>
<th></th>
<th>Participants with TBI (n=13)</th>
<th>Partners (n=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td><strong>Age y; mean(median)(range)</strong></td>
<td>37.61 (38) (23-64)</td>
<td>38.38 (38) (26-66)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Black</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not married</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Married</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>LGBT</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Length of relationship</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;5 y</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>&gt;5 y</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td><strong>Relationship begun</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior to TBI</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>After TBI</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td><strong>Yrs post-TBI</strong>:mean(median)</td>
<td>5.69 (3)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With current partner</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>From previous relationship</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

One of the couples was about to separate when the TBI occurred. They were still together at the time of follow-up interview. One of the couples was lost to follow-up secondary to a health crisis that occurred during the study.

One participant did not fit the strict definitions of TBI adopted by the Houston TBI Rehabilitation Research and Training Center (RRTC) in that injury to her brain was caused not by closed head trauma but by complications during brain surgery. Nonetheless, this individual was regarded by the rehabilitation staff as a person who had had a brain injury, and she had
participated in a TBI rehabilitation program. Given the complex etiology of her brain injury, the PI considered excluding this participant from the study but ultimately included her because she and her partner belonged to an under-represented demographic group, that is, they were a same-sex couple.

Despite efforts to recruit people from racially, ethnically, and sexually diverse samples, this research did not completely fulfill objectives to represent as much as diversity as was hoped for, e.g., there was only one Latino participant and one same-sex couple. Snowball sampling was encouraged, as described earlier, using rehabilitation liaisons for word-of-mouth recruitment in an effort to reach participants from previously unrepresented groups. However, although there were disappointments in meeting some objectives for sample diversity, there were also positive achievements, including having participants who represented a wide range of socioeconomic backgrounds, severity of impairment, couples together both before and after TBI, diverse ages, and both married and unmarried couples. More information about the couples can be found in Table II.

E. Procedures

1. Screening

Prospective volunteers either contacted the investigator directly or were contacted by the investigator or her research advisor after communicating their interest and preferred phone number. In some cases, the uninjured partner was the first contact. However, the investigator always spoke privately with each member of the couple to determine interest in participating before selection. Each participant was screened in terms of the established criteria for inclusion. The purpose of the study was described in detail, including specific activities potential participants would be asked to be involved in. It was shared with the volunteers that there is
currently a lack of knowledge regarding intimacy and TBI, especially from first-hand perspectives and that increasing our understanding would hopefully contribute to recommendations for improved supports and services for people with TBI and their families.

### TABLE II: PARTICIPANT COUPLE PROFILES

<table>
<thead>
<tr>
<th>Couple</th>
<th>Ethnicity</th>
<th>Relat. length</th>
<th>Status</th>
<th>*Ages</th>
<th>Yrs TBI</th>
<th>Employed</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Caucasian</td>
<td>22 y</td>
<td>Married</td>
<td>46/47</td>
<td>3</td>
<td>Partner only</td>
<td>2</td>
</tr>
<tr>
<td>B</td>
<td>Caucasian</td>
<td>35 y</td>
<td>Married</td>
<td>59/61</td>
<td>24</td>
<td>Partner only</td>
<td>2</td>
</tr>
<tr>
<td>C</td>
<td>Caucasian</td>
<td>6 mos</td>
<td>Unmarried</td>
<td>37/29</td>
<td>2</td>
<td>Partner only</td>
<td>---</td>
</tr>
<tr>
<td>D</td>
<td>Caucasian</td>
<td>8 y</td>
<td>Engaged</td>
<td>32/36</td>
<td>1</td>
<td>Partner only</td>
<td>---</td>
</tr>
<tr>
<td>E</td>
<td>AfAm</td>
<td>2 y</td>
<td>Unmarried</td>
<td>42/43</td>
<td>6</td>
<td>Partner/ Survivor volunteers</td>
<td>Surv.- 2</td>
</tr>
<tr>
<td>F</td>
<td>Caucasian</td>
<td>2 y</td>
<td>Married</td>
<td>26/27</td>
<td>1</td>
<td>Partner only</td>
<td>---</td>
</tr>
<tr>
<td>G</td>
<td>Caucasian</td>
<td>22 y</td>
<td>Unmarried</td>
<td>41/42</td>
<td>1</td>
<td>Partner only</td>
<td>1</td>
</tr>
<tr>
<td>H</td>
<td>Caucasian</td>
<td>17 y</td>
<td>Married</td>
<td>42/41</td>
<td>4</td>
<td>Partner (initial/ quit job at f/u)</td>
<td>2</td>
</tr>
<tr>
<td>I</td>
<td>Caucasian</td>
<td>8 y</td>
<td>Married</td>
<td>53/55</td>
<td>2</td>
<td>Partner/ Survivor</td>
<td>2</td>
</tr>
<tr>
<td>J</td>
<td>AfAm</td>
<td>1 y</td>
<td>Unmarried</td>
<td>22/34</td>
<td>2</td>
<td>Partner only</td>
<td>Partner-1</td>
</tr>
<tr>
<td>K</td>
<td>Caucasian</td>
<td>3 y</td>
<td>Married</td>
<td>28/29</td>
<td>10</td>
<td>Partner/ Survivor-student</td>
<td>2</td>
</tr>
<tr>
<td>L</td>
<td>Surv-Caucasian Partn-Hispanic</td>
<td>23 y</td>
<td>Married</td>
<td>47/47</td>
<td>6</td>
<td>Partner only</td>
<td>1</td>
</tr>
<tr>
<td>M</td>
<td>Caucasian</td>
<td>19</td>
<td>Married</td>
<td>46/42</td>
<td>3</td>
<td>Survivor/ Partner</td>
<td>2</td>
</tr>
</tbody>
</table>

*Survivor/Partner ages

Prospective participants were told that they would not directly benefit from involvement in the study, but that they could be contributing to the knowledge base. The prospective
participants were given the opportunity to ask questions or discuss their concerns, their interest in participating was documented, and a time was arranged to obtain consent and conduct the initial interview. Contact information and basic demographic information were also obtained during the screening process.

2. **Informed Consent**

Informed consent was requested of all participants and the purpose and methods of the research were described again to confirm that details of the study were clearly understood. The information discussed with potential participants included the purpose of collecting the information, who the information was for, and how it would be used, what would be asked in the interviews and focus groups, how the responses would be managed, including how confidentiality would be handled, and what the risks and benefits were for the people participating in the study (Patton, 2002). Information was written clearly, simply, and directly to increase understanding of the study. It was very important to assure that written descriptions of the study were clearly communicated and detailed enough for potential participants to make informed choices about their involvement.

All participants who agreed to participate in the study were asked to read and review the informed consent guides. Participants were asked to sign the consent forms and they were issued a copy of the signed consent form for their records. Informed consent was obtained from all participants. Efforts were made to ensure that each participant fully comprehended the verbal and written information by taking as much as time as possible to review all information at least once and encouraging participants to repeat, in their own words, their understanding of the study and their participation in it. Questions were asked of participants to assure that they comprehended the purpose, procedures and their rights to withdraw. Consent was reviewed together with each
participant pausing after each new idea to ask if there was any clarification needed or questions that they had before proceeding to the next sections. Through screening and talking to both partners it was determined that each partner was competent to provide her/his own consent.

F. **Data Collection**

Initial interviews allowed participants to delve deeply into the issues of intimate relationships after TBI and to describe their experiences. Follow-up interviews provided a chance for both researchers and participants to review concepts, themes, issues, and patterns that came up in the initial interviews, to add or change any information and to explore how temporal issues influenced participants’ intimacy experiences. Lastly, focus groups were instructive in giving the participants an opportunity to collectively share, respond to, and validate the themes presented from preliminary analysis of the initial and follow-up interviews.

It was critical that participants felt respected, motivated and comfortable in sharing details about their experiences that were meaningful and significant to them. Because a key tenet of this research was for participants’ first-hand perspectives to guide every phase, participants were routinely encouraged to share whatever they felt was important to their experiences.

1. **Initial Interviews**

Open-ended, semi-structured, in-depth interviews were conducted individually with all study participants in person or by phone to accommodate participants who had challenges with their transportation or simultaneous responsibilities. The interviews took approximately 60 to 90 minutes and were audiotaped and transcribed. Interview guides were generated on the basis of the research literature, input from expert and community advisors, the PI’s and dissertation committee members’ clinical experiences in occupational therapy, rehabilitation psychology, neuropsychology, and input from experts in disability studies. Interview guides are a list of
questions or issues to be examined during the interview. The purpose of the interview guide is to make sure that a certain line of inquiry is being pursued with each participant. The interviewer is free to explore in-depth topics or questions that emerge from the participant’s response and that fit with the overall topics or ideas of the study (Patton, 2002).

The initial interview guide in this study consisted of approximately 25 questions (see Table III and Table IV below) and focused on the impact of TBI on intimacy in the relationship and self-perceptions of participants as intimate persons. The questions explored participants’ perceptions of the strengths and challenges within their relationship in relation to the TBI. The presence of and quality of services and supports related to intimacy after TBI was investigated, as well (e.g. “When it comes to intimacy and having intimate relationships, what services or supports did you find most helpful during or after rehabilitation?”). For couples who were together before the TBI, questions about how their relationship compared prior to and after TBI were asked, (e.g. “Compare your relationship from before your (your partner’s) TBI to after your (your partner’s) TBI. What’s different and what’s the same about your intimate relationship since your (your partner’s) TBI?”) The impact of TBI on participants’ identity and its evolution from initial injury were explored as well.

An effort was made to assure that questions were simplified or modified, as needed, to assure full and fair access. Sometimes participants were asked to repeat questions in their own words to gauge their understanding of any question or statement, when necessary. The interview guide for TBI survivors differed slightly from the guide for intimate partners in that some of the wording or descriptions were simplified or broken down to increase comprehension. Two TBI
TABLE III: INTERVIEW GUIDE FOR TBI SURVIVORS

QUESTIONS:

1. In a couple of sentences, tell me something about yourself as a brain injury survivor.

2. Now in a couple of sentences, tell me something about your partner.

3. What does intimacy mean [to you]? What is an intimate relationship? In your own words, can you describe what an intimate relationship means to you?

4. Tell me about your relationship. Some people feel that their intimate relationships are strong and lasting. Others feel their intimate relationships are fragile and at risk of falling apart. How do you feel about yours?

5. How long have you been together?

6. What do you find most satisfying, if anything, about your intimate relationship?

7. What do you find most difficult, if anything, about your intimate relationship?

8. For couples who have been together Pre-TBI: What was your intimate relationship like before your TBI? Compare your relationship from before your TBI to after your TBI. What’s different and what’s the same about your intimate relationship since your TBI?

9. What factors help make your intimate relationship strong? Or if already answered: You’ve mentioned several things that have helped to keep your relationship strong. What factors do you think help to make things go right?

10. What factors get in the way of a good intimate relationship?

11. How do you and your partner discuss your relationship and its challenges? PROBE: Tell me about how the two of you communicate about your relationship.

12. How has your perception of yourself as an intimate and sexual person been affected since your TBI?

13. Can you share any memories you have of your earliest experiences with people with disabilities? How does acquiring a traumatic disability reform earlier perceptions. To begin to compare whether one’s first exposure to people with disabilities informs one’s present perceptions of disabled people, especially after experiencing a TBI—is this a factor in the ongoing transformation after TBI?
TABLE II: INTERVIEW GUIDE FOR TBI SURVIVORS (continued)

14. How were your early feelings about people with disabilities the same or different from your present ideas about people with disabilities?

15. We’re interested in how images of people of TBI might be shaped, at least in part, by the media. Have you ever noticed the portrayal of people who have had TBI or seen TBI survivors in movies, TV, or books? What were those experiences like, if you can recall them?

16. Some people feel treated differently by others once they’ve had a brain injury; others feel treated pretty much the same as before. What has your experience been of the way you’re treated by others since your injury? PROBE: Have you had the experience of being treated differently since your brain injury, either positively or negatively? How are you treated by your intimate partners, peers, acquaintances, or others in your communities? add... What about your friends, neighbors or co-workers?

17. When it comes to intimacy and having intimate relationships, what services or supports did you find most helpful during or after rehabilitation?

18. What did you find least helpful?

19. If you could say anything to health professionals and counselors to inform them about intimacy and brain injury, what would you want them to know?

20. People with TBI have reported unique challenges related to whether they are male or female. Some people tell us it’s harder if you’re a woman or a man with a TBI.

21. We wonder whether there are specific issues that people face depending on their gender. Tell us about this. [Add: race, sexual orientation, ethnicity when relevant]

22. What services might have helped address the issues that you have had with your intimate relationships or your view of yourself as an intimate and sexual person?

23. How do feel about the importance, if any, of having specialized services for women and men? [or “for...” add relevant category depending upon demographics of participant] should these differences be taken into account when designing programs or services for people with TBI?

24. Can you think of anything else that we haven’t covered that is important to know about intimacy or sexuality and TBI?

25. How was your TBI acquired?

26. Are you employed? How would you describe your daily roles or routines?

_________________________________________________________________
TABLE IV: INTERVIEW GUIDE FOR SIGNIFICANT OTHERS

QUESTIONS:

1. In a couple of sentences, tell me something about yourself as the intimate partner of a brain survivor.
2. Now in a couple of sentences, tell me something about your partner.
3. What does intimacy mean [to you]?
4. Tell me about your relationship. Some people feel that their intimate relationships are strong and lasting. Others feel their intimate relationships are fragile and at risk of falling apart. How do you feel about yours?
5. How long have you been together?
6. What do you find most satisfying, if anything, about your intimate relationship?
7. What do you find most difficult, if anything, about your intimate relationship?
8. For couples who have been together Pre-TBI: What was your intimate relationship like before your partner sustained a TBI? Compare your relationship from before your partner had his/her TBI to after his/her TBI. What’s different and what’s the same about your intimate relationship since your partner’s TBI?
9. What factors help make your intimate relationship strong? Or if already answered: You’ve mentioned several things that have helped to keep your relationship strong. What factors do you think help to make things go right?
10. What factors get in the way of a good intimate relationship?
11. How do you and your partner discuss your relationship and its challenges?
12. How has your perception of yourself as an intimate and sexual person been affected since your partner’s TBI?
13. Can you share any memories you have of your earliest experiences with people with disabilities?
14. How were your early feelings about people with disabilities the same or different from your present ideas about people with disabilities?
15. We’re interested in how images of people with TBI might be shaped, at least in part, by the media. Have you ever noticed the portrayal of people who have had TBI or seen TBI survivors in movies, TBI or books? What were those experiences like, if you can recall them?
16. Some people feel treated differently by others once they’ve had a brain injury experience; others feel treated pretty much the same as before. What has your experience been of the way you’ve been treated by others since your partner’s brain injury, either positively or negatively? How are you treated by your intimate partner, peers, acquaintances, or others in your community? Add...What about your friends, neighbors or co-workers?

17. When it comes to intimacy and having intimate relationships, what services or supports did you find most helpful during or after rehabilitation?

18. What did you find least helpful?

19. If you could say anything to health professionals and counselors to inform them about intimacy and brain injury, what would you want them to know?

20. People with TBI have reported unique challenges related to whether they are male or female. Some people tell us it’s harder if you’re a woman or a man with a TBI. We wonder whether there are specific issues that people face depending on their gender. Tell us about this. [Add: race, sexual orientation, ethnicity when relevant]

21. What services might have helped address the issues that you have had with your intimate relationships or your view of yourself as an intimate and sexual person?

22. How do you feel about the importance, if any, of having specialized services for women and men? [or “for...” add relevant category depending on demographics of participant].

23. Can you think of anything else that we haven’t covered that is important to know about intimacy or sexuality and TBI?

24. How was your partner’s TBI acquired?

25. Are you employed? How would you describe your daily routines or roles?

advocates in the community acted as research consultants during the creation of the research questions. Their input and feedback helped to ensure that the interview questions were relevant to the research topic, respectful, and clear to the prospective participants.

2. Follow-up Interviews

Follow-up interviews (see Tables V and VI) were conducted approximately six months subsequent to the initial interviews to explore the dynamic nature of relationships over time following TBI. The follow-up questions focused on what changes had occurred since the initial
relationship, the quality of couple’s intimacy since initial interview and whether they felt any other services or supports would have helped advance the process of adjustment. Theoretically interesting aspects of data from initial interviews were reviewed with each participant during their follow-up interviews to verify validity of content and to provide an opportunity to change or add any new information.

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**TABLE V: FOLLOW-UP INTERVIEW GUIDES FOR TBI SURVIVORS**

**QUESTIONS:**

1. Since we did our last interview what has life been like for you for the past six months?

2. How do you feel about your relationship over the past six months? What, most recently, has been most satisfying? What has been most difficult?

3. Since we talked what factors would you say have helped make your intimate relationship strong? What factors have helped to make things go right for you and your partner?

4. What factors most recently have acted as challenges or obstacles to you having a good intimate relationship?

5. How has your ability to discuss these or other issues been with your partner lately?

6. How have you felt over the last few months as an intimate or sexual partner?

7. Over the past few months how do you think you’ve been treated by your friends, neighbors, co-workers, or others?

8. Since our last interview and discussion do you have any additional ideas about services that might have been helpful to you with issues you may have had with your intimate relationship or perception of yourself as an intimate partner after TBI?

9. Do you have any final thoughts to share with health professionals or other people who are developing supports for people with TBI?
TABLE VI: FOLLOW-UP INTERVIEW GUIDE FOR SIGNIFICANT OTHERS

QUESTIONS:

1. Since we last talked in our first interview how has life been like for you over the past six months?
2. How do you feel about your intimate relationship lately?
3. Recently, what has been most satisfying about your intimate relationship? What has been the most difficult?
4. What factors have recently been helping to make your intimate relationship strong?
5. What factors are helping to make things go right?
6. What factors recently have been getting in the way of having a good intimate relationship?
7. How has your ability to discuss these issues with your partner been lately?
8. How have you felt over the last few months as an intimate or sexual partner?
9. Over the past few months how do you think you’ve been treated by family, friends, neighbors, co-workers, or others?
10. Since our last interview and discussion do you have any additional ideas to share with health professionals and counselors to help increase their understanding about intimacy and brain injury?
11. What services do you think might have helped to make things better regarding your intimate relationship or your perception of yourself as an intimate partner over these past few months?
12. Do you have any final thoughts to share with health professionals or other people who are developing supports for people with TBI?

3. **Focus Groups**

Focus group interviews were the final method of data collection in this research. Conducting a separate focus group for survivors and for intimate partners allowed for corroboration of initial themes and analyses and an opportunity for participants to openly share their ideas with one another and with the researchers.
The two focus groups were conducted concurrently and moderated by the principal investigator and research advisor. The groups were held at the University of Illinois at Chicago at the Department of Disability and Human Development. The decision to have the groups at this location was made because it was determined that it was the most centrally located and convenient setting for the majority of participants. Some of the participants relied on public transportation and this location was directly accessible to several bus and train lines. The duration of each group was two hours with one 20-minute break after the first hour. After this first hour, the primary investigator and research advisor alternated which group they moderated in order to gain direct experience with all participants and, thereby, strengthening the comparisons and variety of interpretations of the data (Speziale & Carpenter, 2007).

The purpose of the focus groups was to verify and review the themes and responses collected during initial and follow-up interviews with participants and to provide an opportunity to come together for the first time as a group. The participants were offered the opportunity to hear each other’s responses and to contribute additional information as they heard what the other group members said. Patton (2002) states the objective of the focus group is to obtain “high-quality data in a social context where people can consider their own views in the context of the views of others” (p. 386).

The decision to hold separate groups for survivors and partners was made so that participants might feel more comfortable disclosing issues most relevant to them as a TBI survivor or intimate partner without concerns about protecting or offending their partners. Participants were asked to respond openly, thus offering them an opportunity to hear many perspectives and allowing the researchers to examine commonalities within and between groups. To guide group discussion, the researcher presented the preliminary themes garnered from the
interviews and then asked for group member response. This strategy helped to promote accuracy and to clarify the emergent interpretations of participant perspectives. Data collection was completed in 2008.

G. **Data Management and Analysis**

Data from interviews and focus groups were transcribed and organized according to survivor or partner groups, by couples, and by initial, follow-up, or focus group interviews. Completed transcripts were electronically saved, stored, and accessible only to the PI and research advisor. Raw written data were kept in locked cabinets and in these ways the confidentiality of participants was protected.

Initially, interview and focus group transcripts were read thoroughly line-by-line to gain an understanding of the information conveyed by each participant. Words or segments of transcripts were assigned short descriptive labels, or codes, for the purpose of conceptualizing what was found. This process is considered “open” coding (Strauss & Corbin, 1998) because there were no preconceived categories during this first level of analysis. The coding process was continually modified and sharpened as more transcripts were read.

The analysis, like data collection, was informed by a grounded theory framework that enabled emerging concepts to be discovered in the raw data. Immersion in the data facilitated information to be disassembled into manageable pieces with the objective to reconstruct the data into a meaningful whole. The main objectives of grounded theory include trying to find out “what’s going on” or what are the qualities and dynamics of a phenomenon, what are the main problems or concerns of participants and how are they trying to resolve them (Miles & Huberman, 1994; Sandelowski, 1995). Systematic generation of theoretically interesting
interpretations in this study was largely performed utilizing an inductive approach that is, searching for patterns among themes implicit in the data (Patton, 2002). There were also deductive elements inherent in the methods in terms of taking the research questions, objectives and information from existing research into account when trying to understand the phenomenon. Since the overarching objective of this study was to assist people in making sense of their experience and to cope with their situation better, these methods were considered to be the most appropriate.

Additional codes were added as new themes or ideas emerged with the reading of subsequent transcripts. Transcripts that were previously read were read again according to the new codes (or categories) to assess whether they were relevant to them. This circular review, or iterative process, was repeated in order to constantly consider possible meanings and how they fit with developing themes.

When all transcripts were read and no more new themes were found, one-page summaries and reflective memos were created to put “fractured” data back together and develop new ideas that generated potential new conceptualizations about the research questions. An effort was made to find connections or contrasts between themes and subthemes, and these were recorded in the memos in order to gain a fuller understanding of participants’ experiences. For example, there was a connection between a lack of social support and increased perceived relationship fragility for some partners. The reflective memo process enabled a summary representation of relationships between and contrasts among categories or themes that facilitated interpretation development and corroboration of data.

Themes outlined in reflective memos were refined and reduced to the most salient themes or categories in order to reduce redundancy and eliminate overlap among the categories. Major
themes and subthemes that were thought to best capture key aspects of intimacy and TBI issues were organized according to the concepts they described. For example, under the theme “strengths of relationship” some of the identified subthemes included “communication” and “pre-injury strong relationship.” This step was characterized by constantly comparing (constant comparison) data set to data set and then comparing data set to developing theory. “Axial” coding was performed that consisted of reconstructing data by drawing relationships between categories. This process included deductive analysis in that themes were examined in light of existing research and from the perspective of the research questions and objectives. Critically exploring the data contributed to increasing understanding of the participants’ experiences of intimacy after TBI and how the themes related to previous research on this topic. For example, it became evident that many of the uninjured partners associated their loved ones’ expression of love and appreciation with feeling positive about their intimate relationships. This finding challenged and illuminated current TBI relationship research reporting that uninjured partners have less need of validation from their injured mates.

As relevant transcript segments were reconstructed into major themes and subthemes, selected quotations that helped to illustrate the themes were selected. Further exploration of similarities and differences between and across subgroups, e.g. partners and survivors; couples together prior to and following TBI; married and unmarried couples; male versus female survivors and partners; heterosexual couples versus same-sex couple, were performed and themes were further differentiated, when applicable.

A search for contradictory points of views and negative cases was conducted throughout the analysis. Negative cases are responses that do not fit the patterns that emerge in the analysis (Patton, 2002); they challenge researchers to refine their interpretations and to discover new
patterns to fit all of the data. Patton (2002) emphasizes that there are no specific time frames or guidelines to ensure that the search for negative cases is complete. It is the responsibility of the researcher to make a concerted effort to find potentially negative cases and interpret them accordingly. Doing so can increase researchers’ understanding of the issues because it offers alternative ways of viewing information. Patton (2002) suggests that the cases that fall out of the ordinary patterns are sometimes the most informative and interesting components of a qualitative inquiry. A search for contradictory points of views and negative cases was conducted throughout the analysis and contributed to verification of findings. This included identifying and examining information that contrasted from the majority of responses. For example, when encountering unusually positive outcomes in terms of intimacy or communication after TBI, there was an effort to explore the factors that contributed to those incidents so that the analysis would encompass those dynamics. Findings were further explored and verified in these situations to determine if the analysis fit all the data. When there was a question, analysis was refined to address more uncommon responses in the data. For example, one couple admitted to having a more positive relationship after TBI because the survivor had stopped drinking and arguing with his wife and family.

Ensuring thoroughness and depth of exploration using the selected methods helped to increase the trustworthiness of the analysis and interpretation. Rigor and credibility were enhanced through triangulation that is, utilizing multiple data collection methods, investigators and theoretical perspectives to study how intimacy was affected after TBI (Patton, 2002; Miles & Huberman, 1994; Speziale & Carpenter, 2007). Triangulation was incorporated in this research design most clearly through use of multiple methods (namely, semi-structured interviews, focus groups), analysts (the PI and dissertation advisor), multiple informants (TBI survivors and their
partners), and multiple data collection points (initial and follow-up interviews and focus groups). Trustworthiness of the findings was addressed by emphasizing the thoroughness and depth of the methods and by comparing multiple viewpoints, such as the perspectives of the researcher, the advisor, and the participants. Sandelowski (1995) cautions against relying on interpretation that is based exclusively on the perspective of the researcher. Patton (1999) stated that one important way to avoid selective perception and interpretive bias is by having multiple researchers independently analyze the same data set and then compare their interpretations. In this study, the research advisor read and coded selected transcripts and engaged in ongoing discussions regarding emerging themes with the principal investigator to corroborate findings.

Credibility of the investigators is another fundamental element inherent in high-quality qualitative research. The training, experience, and philosophical beliefs of the researchers were important considerations. The PI is an experienced occupational therapist with a specialty in traumatic brain injury (TBI) rehabilitation and is a disability studies doctoral candidate with intensive training in qualitative research. Furthermore, each phase of this project was closely monitored and reviewed by an experienced disability studies and qualitative research scholar and mentor who also has an extensive background in rehabilitation psychology. Additionally, this study included member checking, the process of validating or challenging findings by conveying the researcher’s interpretations to participants for their feedback. According to Patton (1999), “Researchers and evaluators can learn a great deal about the accuracy, fairness, and validity of their data analysis by having the people described in that data analysis react to what is described” (p. 1195-6). In this project, feedback from the participants was sought on more than one occasion. They were given the opportunity to comment on preliminary interpretations during
follow-up interviews and again in the focus groups to assess how reconstructions of the data developed by the researcher related to their personal experience.
V. RESULTS

In this chapter, themes from initial and follow-up interviews and focus groups are discussed separately and then synthesized in the chapter’s conclusion. Direct quotations from the interviews and focus groups are used to illustrate themes and sub-themes. Each quotation is designated as reported by survivors or by partners to offer contextual significance and orientation.

A. Initial Interviews

Six major themes emerged from the initial interviews:

1. Meaning of Intimacy
2. Barriers to Intimacy
3. Factors Supporting Intimacy
4. Loss and Reconstruction
5. Social and Interpersonal Attitudes
6. Health-Care Services and Professionals

In the following section each theme is discussed in detail and further analyzed and categorized according to relevant sub-themes.

1. Meaning of Intimacy

It was enlightening to learn what intimacy meant to each participant first-hand, particularly within the context of her/his TBI experience. The majority of survivors and uninjured partners conceptualized intimacy in similar ways. Four sub-themes comprised participants’ definition of intimacy.
a. **All encompassing**

For the most part, most participants perceived intimacy as an all-encompassing or multi-faceted phenomenon intertwining physical, emotional, spiritual and intellectual dimensions of a relationship. Theories of intimacy (Hook et al, 2003; Gable et al, 2006) also posit that most people express intimacy to comprise of a multitude of variables. The following response from one survivor supports these theories:

“It can mean a lot of different things. It can be talking one on one, but it can also go as far as you know, as sex and everything in between.” (survivor)

One uninjured spouse also echoed this idea of an all-encompassing conceptualization of intimacy:

“Intimacy, to me, is not only a physical aspect but also emotional and mental aspects to relationships” (partner)

Many respondents, in fact, emphasized how physical aspects of their relationship were not the most prominent feature of intimacy for them but only one of many variables. The responses tended to reflect how physical intimacy, although, important, comprising was perceived as only a part of one’s overall intimacy experience. This survivor, for instance, summed it up this way:

“Intimacy is much more than physical. It’s the inner core” (survivor).

Another survivor conceptualized intimacy as incorporating both physical and emotional closeness:

“Uh, closeness, and, sex, too, but it could be sex without intimacy, you know? If you play guitar they’re all waiting at the edge of the stage-that’s not intimacy…That’s just sex, but two people that are attracted to each other more than physically, that’s intimacy” (survivor).

b. **Sex/physical**

A few respondents highlighted the sexual relations or physical aspects of intimacy when describing what intimacy meant to them. These participants identified sexual relations as the
primary characteristic defining intimacy. When asked what her understanding of intimacy was, this partner responded: “Intimacy means a sexual relationship. That’s my understanding” (partner).

Similarly, one survivor conceived of intimacy as: “Um, our love life” (survivor).

Interestingly, these two participants did not reflect such a narrow view of intimacy in the rest of their interviews.

c. Sharing

A large number of respondents identified the concept of sharing as critical which was described as spanning physical, emotional, intellectual and spiritual realms in the deepest ways possible for both survivors and uninjured partners. This idea is reflected in the following responses:

“Well, uh, being able to share your personal life with your wife physically and mentally…” (survivor).

“…to me, intimacy is a sharing of knowledge between two people that most people don’t have. That’s you wouldn’t have, let’s say, with your paper-boy or with the mailman or something like that…” (survivor).

Similarly, many uninjured partners felt that sharing physically and emotionally fostered a closeness that didn’t exist in other types of pairings. It was this closest level of intimacy that was identified by some partners:

“I think having a partner or someone that you can share all aspects of yourself with” (partner).

“It means sharing your life with somebody on the closest possible level” (partner).

In fact, being totally open and honest with another person by sharing emotionally and physically defined intimacy for this respondent:

“Intimacy means sharing your feelings and thoughts. Touching, being absolutely open and honest to somebody else” (partner).
Sharing was also expressed as a concept of having a lifelong confidante or “soul-mate” by some.

“Um, the person being your companion, you know, your mate for life, your friend” (partner).

“It means like soul mate, um, like someone you became one with and also, best friends and have this intimacy with. It’s like a oneness, or whatever” (partner).

Some participants conceptualized sharing as juggling day to day issues as well as having someone to rely on when things were difficult. Both survivors and partners articulated sharing as spending time together and being there for each other. In fact, being there for each other was often conceived in both small and large ways:

“…sharing things, you know, every day family things, big decisions, and, being there when you need someone…when you’re having a bad day, and physical…yeah, that’s what it means to me” (partner).

Feeling comfortable to be vulnerable with another person also was described as sharing on an emotional level. For instance, this survivor expressed how being vulnerable to her partner also allowed her to feel closer to him:

“…intimacy, for me, would mean the sharing of emotional, spiritual and physical sharing the deepest, most vulnerable side of myself with another, my partner, my husband…” (survivor).

Finally, the aspect of sharing is reflected in this uninjured partner’s comment:

“To me having C. hold me in his arms and, and just sharing whatever comes in our mind. Just holding to, holding each other” (partner).

d. **Caring for each other**

Many respondents also defined intimacy as each partner mutually caring about each other. Caring was demonstrated by feeling listened to, showing affection and spending time together. Interestingly, this factor was generally expressed more by the survivors, perhaps due to the fact that uninjured partners may have been doing a larger share of the caring since their mates’ injury.
The essence of intimacy was taking the time to listen and support each other for many participants. These responses echo these sentiments:

“Well, somebody that supports me, and listens…and we care for each other” (survivor).

“…the intimacy would have to be just me caring for him, him caring for me, us caring…” (survivor).

Doing things together or companionship was also an important component of showing that one cared about their partner. This survivor likened doing even small things with his partner as heightening the intimacy between them:

“…You go out, you know, you do stuff, even those little things makes a difference” (survivor).

In summary, both survivors and partners, for the most part, unanimously described intimacy as a complex process that spanned a multitude of factors much beyond the physical aspects of being with each other. Sharing on many levels, spending time together, relying on and being there for each other and being willing to accept one another, even with significant changes, individually, and as a couple were considered critical to constituting intimacy for these participants.

2. **Barriers to Intimacy**

   **Survivors**

   Within the theme “barriers to intimacy” there were a number of issues or perspectives unique to survivors and uninjured partners; therefore, they are discussed separately according to these respective groups in order to illustrate their unique experiences. Survivors’ responses precede partners’ responses and are followed by a discussion of survivors’ and partners’ commonly identified themes.
a. **Injury related changes**

One of the most commonly expressed issues about difficulties intimacy after TBI, according to most of the survivors was their perception that their physical, intellectual or emotional status declined since their injuries and interfered with their expression of intimacy. Many of the survivors acknowledged significant differences in their abilities and opportunities for intimacy as compared to before their TBI. This contributed to a general sense of inadequacy, decreased confidence in one’s abilities and a tendency to compare one’s life between pre-TBI and post-TBI. Survivors of both genders conceived of not being physically fit or attractive enough or being able to express intimacy adequately to be a satisfactory intimate partner since their TBI’s. However, there were more responses related to these issues from male versus female survivors, which may have been at least partially secondary to the fact that there were more male versus TBI survivors participating in this study.

b. **Physical changes**

Physically expressing one’s love or affection to their partners was one of the most common forms of intimacy targeted as negatively impacted by changes since injury. Quite a few respondents expressed experiencing a disassociation between the affection and passion they felt and their inability to sufficiently express these desires to their intimate partners. There was a feeling by some respondents of being incapable of giving their partners “real” passion because their bodies would not move in the ways they felt they should in order to demonstrate sexiness or desirability. This idea was communicated by one woman survivor in this way:

“…not being able to give him a real hug…Well, even just like-kisses. Because my right side has been affected I’m not even able to give him a kiss, like a real kiss…I think just the passion that goes in to it? Like the long of a, like a longer hug and a longer kiss, too”. (survivor)
Similarly, many of the men survivors intimated that they felt like they were not “real men” due to organic changes such as having a low libido or experiencing premature ejaculation since injury. Many of the men survivors expressed a feeling of being out of sync with their partner’s needs.

There was a suggestion by some of the respondents of not living up to their own or societal ideals of masculinity. Some of the men survivors voiced remorse or guilt over not being a “macho” man. Some male survivors felt that not being able to fulfill socially constructed ideas of “masculinity” or “machosism” made them feel diminished and they grieved the loss of power or strength that they equated with “normal” male sexual roles. There was a sense of not living up to the “male” ideal as “bread-winner” or “stronger sex” because of physical or cognitive changes. The internalization of mainstream constructions of male gender ideals created tension as poignantly expressed in the following:

“A lot of the guys that I go to therapy with that were sort of blue collar guys, and were supposed to be at work and fixing the car and carrying your wife upstairs in your arms and these macho things and paying the bills and before I crashed they called me ‘The grand poo bah’ from the Flintstones, you know? I’ve got a shirt and everything. I ain’t the ‘grand poo bah’ anymore. And that’s really disheartening”. (survivor)

TBI negatively impacted many of the men survivors’ sense of self as an intimate partner due to the presence of physical or organic impairments:

“…and as a man, some of those difficulties make you feel, you know, like less than a man, like not a complete person, and, as if you’re letting that other person down all the time…because your whole life as a man you’ve got to be strong and be able to do this and that and when you can’t do that anymore, you feel like you’re not a man anymore because you can’t function the way other men can”. (survivor)

Some survivors echoed the concept of feeling inadequate as a man, sexually, since their TBI:

“Sex is kind of difficult. Because I cannot perform with her like I choose to, like I want to…” (survivor)
“I have less, it makes less urgings…Like, it’s less often, now once a week, every ten days, something like that. It kind of makes me feel bad about myself now that it’s so different. I ask D., ‘Hey there’s this other handsome guy, you know, you could have this regular guy one time’…”. (survivor)

c. Cognitive changes

Perception of altered cognitive skills directly impacted the quantity and quality of the companionship some participants felt they could offer their partners. They related how cognitive changes presented as barriers to achieving satisfactory feelings of “closeness” to one’s mate. In fact, many survivors described being unable to think quickly or to adjust to changes well and, thus, felt that they lacked the ability to be fun-loving, flirtatious and adventurous with their partners. These characteristics were identified as having been important, prior to their TBI, in creating an atmosphere conducive to intimacy. For example, this survivor lamented her lack of ability to be spontaneous due to cognitive changes and that this created problems in both her expression and identity as an intimate partner:

“…before I thought of myself as adventurous and kind of just full of energy constantly ready to go type of a person…there’s no spontaneity with me. It seems like there can’t be any unplanned time sharing with each other. I have to mentally know when it’s going to happen so I can prepare because I can’t switch gears anymore”. (survivor)

Mental fatigue from having to concentrate harder since TBI because of cognitive limitations made one survivor feel as if he had less patience, which had a negative effect on how he communicated with his loved one:

“…My patience is short and I get irritated and then I’m easily irritable because I’m mentally tired”. (survivor)

d. Emotional changes

Emotional changes since TBI also took their toll on intimacy according to a couple of women. For instance, one survivor described how her feelings of inadequacy manifested when she felt she couldn’t provide emotionally to her spouse when he was in the hospital with his own illness:
“Um, I try to be but basically I don’t think I am really….like when he was in the hospital with his cancer stuff it was like I was there but, it was like the person who should be there wasn’t there, you know what I’m trying to say? He had a person there but not the person…oh, I wish I could put it into words, but it’s just that it’s just that”. (survivor)

This same survivor admitted that communicating with her partner was strained because her inability to control her emotions:

“…I don’t talk as well as I used to talk, you know? Especially like sharing things with B. I just can’t, especially when it’s upsetting stuff I can’t because I start crying real soon and I never used to do that…”. (survivor)

Another woman expressed how physical changes from her TBI made her feel insecure about herself and so she tended to close up emotionally:

“The most difficult part of it is because I feel like physically there’s been challenges that especially since my accident there wasn’t anything before…when it comes to any physical intimacy I am dealing with insecurities and things about myself just that have come from the accident…to prevent me from being in the mood for physical intimacy…we’re out of sync… my own thinking gets in the way and I kind of close up and I don’t communicate and that ends up putting a barrier between us to where we don’t feel open to share deeper intimacy with each other”. (survivor)

Survivors perceived role loss as perpetuated by physical, cognitive or emotional impairments rather than from social factors such as stereotypes, low expectations of people with brain injury or lack of accessible services. These issues will be addressed in further detail in the discussion section.

e. Guilt

Guilt manifested itself in a variety of ways and was prevalent, in some form, among almost all survivors. Largely, survivors had varying degrees of guilt stemming from their TBI that included feeling as if they couldn’t provide sexually, consequently, leaving their partners unfulfilled or contributing to their partners stress and fatigue by adding responsibilities that they believed they should be sharing, if they were able to.
f. Letting partner down sexually

Letting their partners down during intimacy was echoed by some of the men survivors as a problem that caused them to feel as if they were not living up to their partners’ expectations. Not being able to sexually perform or satisfy their partners either as they used to do or how they believed a “normal” man should proved to be very problematic for some of the men.

“…and, sometimes, it’s getting late and she has to get up early, and she’s already had one already, sometimes it makes me feel bad that it’s so much different than it was before. Like my cardiovascular, I’m tiring out”. (survivor)

Some of the men articulated feeling disconnected from “normal” male expressions of intimacy and how they believed other men with disabilities had to re-negotiate their own sense of “maleness” since injury. For example, this respondent expressed this idea this way:

“…Things don’t, you know, not just sexual functions, but, your limbs don’t move the way you want them to. You can’t get words out the way you want to, and, it’s difficult and, even though your brain’s saying ‘Do this’, it’s not happening. And that’s a difficulty to overcome, and, as a man, some of those difficulties make you feel, you know, like less than a man, like not a complete person, and, as if you’re letting that other person down all the time…” (survivor)

g. Not pulling fair weight with responsibilities

Other respondents focused on the additional responsibilities their partners had to absorb since their injuries. This type of guilt was shared by both men and women participants and included employment but also every day activities around the home that they could not perform any longer because of physical or cognitive deficits. Many survivors talked about feeling guilty and responsible for the added stress and fatigue that their partners had because of having to do more to compensate for their limitations. The inability to contribute financially or physically to the day to day responsibilities was identified as a source of significant stress in their intimate relationships.
“...but the brain injury causes stress in a lot more things that, um…there’s less things that I do now and there’s more things that D. does now. So if you already have a full-time job and a commute full of responsibilities and two kids and a house and a dog and a cat and dinner and everything else then me just adds to it…so, sometimes she says, ‘It’s like having 3 kids sometimes’”. (survivor)

One participant shared the emotional consequences of having his spouse take on more responsibilities, and as a man, not living up to the expected “male” roles of taking care of one’s partner:

“There’s sort of, the guy thing, the guilt thing, or the sort of feeling less than before for doing the house things and working, being driven everywhere you go by your wife instead of driving her and letting her relax…”. (survivor)

Women survivors, too, reported increased stress due to having their partners take on additional responsibilities.

“…there’s things that we’ve done at home that he’s kind of like he has to do himself that he’s taken over seeing as I had the brain injury. Especially like stupid stuff like grocery shopping, you know. I still can clean the house but grocery shopping and cooking I can’t do those things anymore”. (survivor)

This idea was reflected, as well, within the relationship between one same sexed couple:

“…and for her part, not being equal in the relationship. I’m not pulling my fair weight...There’s a lot of stress on our relationship; with taking care of our son, dogs, a lot more responsibilities”. (survivor)

Some survivors felt the stress because their inability to work meant their partners had to work additional hours and this resulted in having less time to spend together:

“...we are worrying...because we’re down to the one income, um, there’s more on our plate now and not, where we were taking the time to enjoy each other before the accident, now we have to make a conscious effort to do it because there’s so much whether it’s appointments or my husband having to work extra jobs, and time not together, because I can’t work and I don’t have an income coming in...”. (survivor)

h. Partner infantilizing/not trusting

Some survivors expressed frustration because of their partner’s lack of confidence in their abilities since their TBI. The lack of trust or feeling infantilized was a barrier to intimacy
because of the way it significantly shifted the balance from two adult partners to an adult and child relationship. The surveillance that some respondents said they felt from their partners caused a lot of stress and resentment. One survivor attributed changes in intimacy since his TBI to his spouse’s tendency to second guess him:

“…Having to answer questions when you don’t want to answer them…You know, it seems like that period of time keeps coming back up. You know, as far as, ‘You’ve got to be careful about this, you’ve got to be careful about that’ “. (survivor)

One woman complained that her partner’s caused a lot of tension in their relationship:

“Distrust in ‘Did you do this?’ ‘Yes, I’m sure’. ‘Are you positive’? ‘Yes, I’m positive’. My partner isn’t confident in what I can and can’t do and what I can remember.” (survivor)

i. **Partner skeptical to resume sexual relations**

A couple of survivors admitted there was tension because of their partners’ trepidation about engaging in sexual activities with them since their injuries. They felt that it was difficult to create an atmosphere of intimacy when their partners were concerned about whether they could engage physically or cognitively with them:

“Oh yeah, big time. Big time. She’s uh, ‘Hey, you gotta ask the doctor’s permission to do this, you know, you had this big crash, you’re supposed to be resting, not physical exertion’, and you know, she was being very cautious”. (survivor)

j. **Unsupportive or unavailable family**

The majority of participants cited family members as very supportive to them individually and as a couple after TBI. However, one couple reported their family to be surprisingly hostile and unsupportive after their daughter in law sustained her TBI. This survivor felt that her in-laws lack of support was harmful to her and her partner’s overall adjustment and contributed to stress in their relationship:

“Family members that we never expected to respond the way they have have responded negatively and that’s been a hard thing to deal with… I’ve now been identified more of a shame and guilt way about it and saying that I shouldn’t have been out gallivanting because otherwise
the accident wouldn’t have happened and kind of coming at it from the standpoint of how I’ve destroyed S. life and that he has all this now to deal with and things like that”. (survivor)

Another survivor described how her spouse had to confront challenges created by her TBI mostly on his own because support of their family dwindled over time. She felt that there was family support early on after her TBI but that it gradually diminished and her spouse had to take up the slack. This contributed to tension in their relationship, according to her account:

“B. has had to deal with it his whole life, and it’s like, he’s had to face different things that a lot of people, I mean, it’s not that they don’t want to be close to you but they take a step back, instead of taking the step forward they’re taking a step back. And really…relatives, everybody has done that…B. is the only one who can’t ignore it. It’s there to stay…”. (survivor)

k. Resignation of partner seeking others’ companionship

This theme emerged only from one participant. She and her uninjured spouse were in their late 60’s, and were the oldest couple among the participants. Their circumstances were unique as well in terms of the fact that this survivor sustained her TBI approximately 30 years ago when she was 25 years old. Essentially, this couple had been together for more years after TBI than prior to it. These factors may have impacted the particular struggles they had regarding the partner desiring other women companionship:

“…he has a life of his own…He has friends that I’ve never ever met…He has a life that he pursues on his own that’s kind of like separate from the life with me…he’s got to have his area where he can breathe, you know what I mean?” (survivor)

Partners

a. Survivor “not the same person”

Challenges to intimacy for all the uninjured partners were centered broadly on changes since their loved one’s TBI, both for couples together prior to TBI as well as for couples who met following TBI. The accounts from the latter group were essentially comprised from perspectives of their loved ones or their family members as opposed to first hand experiences of
partners with their mates before their TBI. Moreover, reported changes from post-TBI partners were largely focused on the impact of TBI on their loved one’s pursuit of goals or pre-morbid personalities. In contrast, changes identified by pre-TBI partners were more significant for the ways in which they believed their loved one’s sexual or intimate communication styles, cognitive or physical deficits and both partners day to day routines and roles affected the integrity and balance of their intimate relationships. Uninjured partners with their loved ones prior to their TBI also shared how they were personally transformed, on multiple levels, as a result of their partners’ changes.

Uninjured partners, in general, seemed particularly vulnerable to change because of the acute and frequently permanent nature of the changes, the lack of general understanding of TBI, lack of supports especially long-term and the lack of skills partners were equipped with to manage the daily struggles and phases of recovery and adjustment. The following changes are described in further details.

b. Cognitive and emotional changes

The predominant feeling regarding change after TBI was that one’s partner changed in significant and far reaching ways, even though, in most cases, the “core” or “soul” of the person was intact, according to their partners. Couples together prior to one partner’s TBI described how different, in various ways.

Changes in one’s partner’s personality were often described as so profound as to feel as though they were with a different person entirely. This respondent articulated that she felt as if her husband were a different person because of his cognitive and emotional differences from his pre-morbid state:

“…he’s a different person, you know. And, we did go to a psychologist, a psychiatrist, one of, a therapist after his injury, um, family therapy, and, um, so, when I told him it’s like being
married to a different man, he said, ‘Well, that could be good, but, I said, ‘But, I don’t know him, so it’s kind of odd’’. (partner)

Hurtful or insensitive remarks or behaviors made by the injured partner as a result of injured partner’s head injury had a deleterious effect on intimacy. Some of the participants reported that their partner’s TBI made them less sensitive or able to appreciate other people’s perspectives. This caused a lot of stress and feelings that were not conducive to intimacy:

“Um, I’m irritable. And, then you know, just off the wall stuff that M. says that bothers me…for as sweet as M. is, and I’m sure there are other people who find this too, he can be, sometimes he says whatever comes to mind, and sometimes it’s hurtful, or, it’s not, I don’t want to be with you, I, we need some space here, that’s what I find very difficult. I find myself, I want to back off a little bit. I don’t want to be with you in an intimate way”. (partner)

The inability to share with one’s intimate partner on intellectual was reported as constraining and a departure to how one’s relationship was prior to injury. One respondent described how his partner’s injury prevented them from enjoying this element of their relationship like they did previously:

“It’s difficult because I’m interested in current affairs and she has no interest in that. She barely knows who the president or vice president is…what I miss is that we both used to read, she can’t read anymore. We would go to the movies and discuss them afterwards. Now I have to explain them to her unless they’re very simplistic”. (partner)

Emotionally, sharing with one’s intimate partner was an extremely important part of most people’s relationships. Some partners felt that although the physical manifestations of intimacy might have been reasonably intact, the emotional closeness that characterized their unique intimacy with their loved one was vastly different. This is expressed by these partners:

“…Our sex relationship is good. Like I said, I would like more of the just hugging and kissing, and the nurturing, that kind of loving feeling that isn’t quite there that much” (partner)

“I think an intimate moment is one you pour your heart out. And, we can’t do that anymore… It’s the lingering and holding…we don’t have that anymore and that’s what I miss the most” (partner).
c. **Sexual changes**

Changes in loved ones sexual abilities and style as compared to pre-TBI troubled some participants. Some of the changes were characterized by partners not remembering how they performed sexual relations prior to injury and having difficulty with physical expressions of intimacy. Other people felt that changes were the result of their partners not having as strong sexual drive as prior to their injuries. One partner felt that her intimate relations changed from being very passionate to “nice and sweet”:

“Well, I miss the partner that he was because even though he is loving and caring now, everything is, uh, it’s very timed for him if we have an intimate relationship. It’s very sweet and short… and, I guess I miss the lingering part of, you know, just staying together and holding each other, and talking maybe for a while. I miss that. We have that intimacy, but it’s not, and it is close. But it has a different quality to it. And the quality that I so greatly miss because that’s why I chose him. We were such good partners…” (partner)

Other partners lamented that their passion or intimacy was completely gone since their loved one’s injury:

“I feel that passion is missing from my life and it’s extremely bothersome to me”. (partner)

Profound change in survivors sometimes left partners feeling as if they were with an entirely different mate. This partner relates how disconcerting this felt for her:

“…But, it’s weird that he doesn’t remember that. Different things that he used to do he doesn’t remember, he doesn’t even, he has no clue about it…it’s very different to me. It’s like I’m sleeping with another different person and that’s very unsettling”. (partner)

A few of the participants expressed having difficulty dealing with the emotional outbursts that their loved ones sometimes had as this had the effect of diminishing their sexual or intimate feelings towards their partners, at least during and following the moments of the outbursts. This spanned both genders. One male respondent, for instance, expressed a
dampening of his sexual feelings resulting from his spouses’ tendency towards emotional outbursts:

“…But, it’s very difficult because she’s very childlike and having sex with her is like having sex with your child. I love her dearly but it’s a different type of love that it used to be. You’re more like a parent than a husband. Sometimes I want to hug her in bed and she’ll say, ‘Get the hell out of here’. Sometimes she’ll want to be more frisky but at point it’s lost it’s appeal”. (partner)

In fact the disparate states of witnessing one’s partner having a temper tantrum one minute and then making sexual advances the next were very disconcerting for some participants. The realities of behavioral problems caused by TBI made it difficult for some partners to feel as if their role as intimate partner was relevant any longer:

“…If I have a relationship with this man, am I having a relationship with a man or a child?...And that was one thing that really kind of hung over me all the time. Because at one minute he’s having this outburst like a tantrum and then you’re going to have…you’re going to make love to this person?” (partner)

One spouse felt that her partner demonstrated intimacy differently in an attempt to try to “prove himself” and felt that this was a male sort of characteristic:

“…there is a difference in our relationship, you know, intimate wise, you know, and I think more so, especially being a man, I think my husband feels that he’s got to prove even more so that’s he’s a man…”. (partner)

d. Role conflict

This theme resonated with the previous one in that partners struggled with feeling as if their role as intimate partner conflicted with feeling as if they were more like a caregiver providing to a child due to the previously described changes reported. Many of the partners shared a sense of their roles shifting in relation to increased responsibility, stress and changes directly associated with their partner’s TBI. Tangibly taking on parental duties underscored the tensions that caused a negative impact on intimate relationships. Negotiating “parent”
with intimate partner role due to cognitive and behavioral changes was very challenging for many participants. One role seemed to “cancel out” the other one in deep and troubling ways that were difficult to know how to come to terms with for these respondents. This was particularly salient in descriptions of the struggles some participants had with the dissonant experiences of “parental” figure and intimate partner.

“I’m the wife of a husband who has a traumatic brain injury, it will be 3 years now since his accident, and sometimes I feel more of a caretaker than I do a spouse, that’s how I feel at this point in our relationship…I’m tired and irritable, and, sometimes I feel bad, like I’ve lost that wife position. I’m so busy taking care of everybody, you know …”. (partner)

Others echoed feeling as if their own emotional needs were compromised because they devoted so much physical and mental energy towards being a caregiver to their partners. For example, this response reflects this idea:

“…I became such a caregiver that it’s kind of hard to think of my needs…” (partner)

Some of the partners commented on their lack of confidence in their loved one’s abilities contributing to their feeling that the intimacy in their relationships was being “chipped away at” and their “adult intimate partner” role was further being eroded. Many partners shared they felt the need to be on constant surveillance or “high alert” in case any emergent situations needed their attention. They related how this counteracted feelings of intimacy and passion in their relationships:

“…. It’s deteriorated more to a parent-child relationship which neither of us want it to be…if you’re afraid somebody’s gonna leave the stove on it’s hard to get out of that mode. I do hope it changes. And, I’m trying really hard to not to hover and give her space but, there’s also the safety of a child in this”. (partner)

A few of the partners struggled with the balance between wanting to support and care for their injured partner while simultaneously acknowledging the need to facilitate opportunities for
their partner to develop survival skills. This was expressed, not surprisingly, as quite a challenging and stressful process in the sense that it was difficult to know how much to be a caregiver and how much to foster independence. One participant expressed this juggling process in her intimate relationship with her boyfriend whom she met after his injury:

“I think that there are for sure some challenges as far as trying to balance the role of being in a relationship with someone with a disability and also care-giving and trying to make sure that my needs are being met as far as making sure the majority of my time is spent in the role of being a girlfriend versus how to access like humor to make sure that I’m not feeling like I’m in the role of a caregiver and I have choices with that piece”. (partner)

One partner who met her boyfriend following his TBI talked about the frustration of not having her needs met emotionally:

“…he tells me he loves me and I really do believe he does but I don’t see where he can meet my needs and I’ve discovered that. So, and that’s why it’s kind of difficult for me to stay connected in that way…Yeah, because I’m not getting all my needs met. And, so, that’s sort of unfair because everybody deserves to have their needs met, you know?” (partner)

e. Communication difficulties

Difficulties communicating with survivors because of emotional, intellectual, or behavioral changes from their brain injuries contributed to a sense of unmet needs for their partners. Many of the partners spoke about feeling a disconnection emotionally with their loved ones. Partners also reported that they often felt they needed to overcompensate to make up for their loved one’s inability to express themselves effectively.

One partner related that she felt unsatisfied and disappointed when her partner didn’t communicate that he loved her either verbally or physically. Some expression of love, it seemed, was critical to her sense of relationship well-being:

“The most difficult is if he doesn’t tell me that he loves me…and if we don’t have that lingering moment after you, you have intercourse, you know…”. (partner)
Many partners felt that their mates often misconstrued some communication between them because they had difficulty picking up on nuances or interpreting meanings. One partner shared that tensions in her intimate relationship including arguing with each other and that they never did this pre-injury:

“…we’re not thinking on the same wave length. When I say something she takes it differently than I mean it, when she says something, she doesn’t say a whole lot, it comes out angry and not communicative…we avoid talking about it. Or, we yell at each other and argue which we never used to do”. (partner)

Communication became superficial and shallow after some injuries and this had an injurious effect on relationships:

“…he really didn’t talk to me very much. I mean, it was really, really shallow. I would have to ask him 50 million questions and I would get upset because it’s like pulling teeth and um, I mean, I knew he didn’t do it on purpose….You have to really know what you want from him and ask the question in kind of the right way”. (partner)

Difficulties communicating were noted to be a challenge with a couple who was not together prior to TBI. This partner expressed feeling discouraged that she consistently had to explain things to her boyfriend. The additional efforts she had to make to compensate for his limitations made her question whether the relationship was worth it:

“With M., you have to sort of, he jumps to conclusions and he’ll get the wrong understanding. If you talk to him he’ll just, he interprets things wrong sometimes. And, it’s sort of depressing having to break down everything that I really shouldn’t, you know?...it’s like too much for a girlfriend”. (partner)

f. Balance/Stress

Several of the respondents felt that having additional responsibilities since their significant other’s TBI contributed to increased levels of stress, fatigue and overall negative impact on intimacy. Intimacy was potentially vulnerable to becoming fragile or disintegrating in the setting of chronic or traumatic stress. Couples already under stress often are asked to take on
more responsibilities and come to grips with often acute and profound changes in their relationships at a time when they can least handle any more stress (Godwin et al., 2011).

“...That financial responsibility has all been shifted to me now, since the accident....M. does not drive, I do all the driving. M. does not work. Um, I work outside the home. ...Sometimes, when I’ve had a bad day, you know, I just want somebody to take care of me, and, that’s that’s just not there, you know? What it was before is not what it is now”. (partner)

Interesting, even for partners who met after TBI, there was an acknowledgement that they had additional responsibilities than may have existed if their loved one did not have an injury. For example, one spouse commented on how she had to assume a more “take charge” position in getting ready for the day:

“Well, I feel like in the mornings, I have to kind of be the one to help get him going and get him to get up and ask him to do certain things as far as...maybe, more I have to be the one to be responsible for making sure things are done...”. (partner)

Additional responsibilities were especially challenging within relationships in which the commitment was rocky preceding the injury. This is illustrated in this response in which one partner cited the responsibility of having to take care of her spouse was all the more shocking because they were planning on separating prior to his injury:

“...So, I, you know, cause when this happened we weren’t together so it was a big shock to have to be put in that responsibility, you know, the responsibility of taking care of him when he was supposed to be leaving that weekend, when I thought I was rid of him. I was like, ‘Oh, gosh’ “. (partner)

g. Relationship strong and fragile

Many partners described how their intimate relationships were both strong and fragile. This dissonance was a source of struggle as was reflected in the responses. Fragility seemed to be prevalent common strand in relationships and associated with often profound and permanent changes in survivors, and thus, in the partners and their overall relationships as well. The
following participant reflected these ideas and the fact that it took quite a bit of effort to make the relationship work again:

“It’s both…it’s strong and we consider it to be everlasting, but, when you have somebody that’s gone through, that has TBI it’s also very fragile. I mean, this person is changed the wearing of their thinking pattern and their motions and they have changed and it takes a lot of trying to work together”. (partner)

Putting in the “hard work” to re-build intimacy while confronting how fragile one’s relationship has become was a common idea as the following implies:

“…Fragile only because of the fact that you’re worried about him. And certainly there have been many many reasons to worry as things have changed…I think that if I wanted to let this marriage go, I probably would have a long time ago because of the struggles that we had…” (partner)

The ambivalence of feeling the relationship was strong and at risk to deteriorate was articulated this way:

“There are days that I mean, and I know this sounds crazy, that I feel really strong that we’re going to make it through this, we’ve made it through this far, we have been together for twenty years, we’ve been married for seventeen, and there are days that I think, ‘Oh, my gosh, you know, it’s a bad day. Are we gonna make it’? (partner)

Fragility sometimes manifested itself as a result of the combination of day to day stresses and insecurities of some survivors’ feelings of inadequacy. This required one spouse to provide reassurance to her loved one above and beyond the other things she juggled on a regular basis:

“…Just from day to day stresses of him feeling incompetent, or him feeling not providing towards the family to me rushing around to take care of everybody. So, on a day to day basis…I feel we’re not gonna make it, but, I do have those days…and I’m sure he does also…I think he needs more reassurance now since the accident than ever. I don’t recall reassuring him like that…” (partner)

Other respondents felt that their relationships were strong only based on previous commitment versus current functioning:

“At this current moment I feel that it’s very fragile. But, we’ve been together for 23 years and it’s built on a very solid foundation so I don’t think it’s gonna fall apart all together, but the roof is swaying on a really tall building”. (partner)
h. TBI reflecting own weaknesses

Partners, like survivors, shared specific barriers they felt existed in their relationships that interfered with intimacy. Many survivors expressed feeling vulnerable in various contexts but only one uninjured partner’s voiced vulnerability about his own capabilities as a result of his spouse’s TBI. It seemed as if this participant was internalizing relationship challenges as a reflection of his own incompetence at not being unable to compensate for any problems that emerged since his partner’s injury. He couldn’t live up to societal gender images of the “male” as a “hero”, bread-winner or “coming to the rescue” when the need arises. Feeling insecure about not living up to expected gender roles as a man seemed to be taking its toll on the buoyancy of his intimate relationship:

“…I’m a man and I’m supposed to be able to take care of myself. I’m supposed to be able to pay and, you know, do this. But, you know, we’re down to one income, so what am I gonna do? I had to ask my mother-in-law, ‘Can I move in’? I was at the mercy of people, of my mother-in-law…and I’d like to be able to be the one who’s like, ‘All right, you know, you’re going to do this and this is what’s gonna happen. And I didn’t have that kind of control. I don’t, I don’t have that power. I don’t. So I had to face that”. (partner)

i. Tentative about pursuing sexual relations

Some partners voiced concern regarding whether their loved ones were physically, cognitively or emotionally equipped to engage in sexual relations since their injuries. Some respondents said they worried about whether their partners could withstand the “stress” of physical relations. Others questioned whether their partners were emotionally or intellectually ready to handle it:

“I was afraid to even get intimate with C. because my greatest concern was ‘What is his IQ?’ ‘If I have a relationship with this man, am I having a relationship with a man or a child’?” (partner)

This spouse expressed anxiety about re-establishing physical intimacy with his partner since her injury:
“…We go like a month at a time not having, not making love, and I know that hurt A., but, I was kind of feeling awkward about things…” (partner).

Respondents who admitted to feeling unsure about how to go about re-establishing intimacy reported not having had any information or education regarding intimacy after TBI.

j. Family factors

Lack of support from family members served as another factor that negatively impacted relationships for some of the participants. One partner clearly was disappointed in the lack of support he and his wife received from his own parents and this seemed to take a toll on the relationship:

“…I had to face that no supportiveness from my parents and from my family of origin and their lack of dealing with it, so I had to distance myself because I have to be here for my wife and me and I have to be grounded in reality and face the reality of the accident every day”. (partner)

Other people reported how their families were sort of absent and, thus, being unable to be a source of support:

“Her family, her brothers and sisters, they just kind of ignore us”. (partner)

One partner discussed how her family appropriately had some concerns about her dating a man who had a TBI but that their doubts about the relationship was a detriment to feeling like she could confide in them:

“…from their perspective their family members’ dating someone with a disability that I’m going to be in a care-giving role with this person. I think it’s just easier if the family and close friends approve of the relationship instead of having to have a lot of dialogue about this is why this happening. There are some valid concerns from a family’s perspective but, that is frustrating”. (partner)

3. Factors supporting intimacy

When asked what characteristics contributed to making or keeping relationships strong, both survivors and partners shared numerous reasons regarding why their intimate relationships
were thriving, even in the aftermath of TBI. This is illuminating because of the limited first-hand accounts from TBI survivors sharing the positive aspects of their relationships (Godwin et al., 2011). Within the TBI literature, there is a tendency to focus on the negative consequences of injury relevant to long-term adjustment and family dynamics (Vangel et al., 2011). Fewer inquiries exist that explore potential positive factors bolstering interpersonal relationships. Many of the responses gathered in this study suggested that there are indeed several tangible things that reinforce intimacy and affirm one’s commitment even after the occurrence of catastrophic events such TBI. Sub-themes that follow describe the factors related to supporting intimacy in the context of TBI.

There were three themes common among survivor and uninjured partners and they are discussed together. The next section describes the themes unique to survivors followed by a description of themes unique to uninjured partners.

a. Themes shared by survivors and uninjured partners

   i. Good Communication

(Survivors)

Almost all the survivors shared that fostering good communication helped to keep their relationships strong. Many respondents emphasized the importance of resolving, through discussion various problems that emerged. There was an appreciation for both the arduous nature of this effort, but, ultimately, effective outcome, of talking through every day challenges, for most of the survivors. Most felt that they communicated effectively with their partners, in part, because they talked through difficulties on a regular basis and, thus, avoided otherwise, potential conflicts with their mates:

“…sometimes we don’t agree on the same, um, idea that we keep talking about it and talking about it, talking about it until finally, which may take maybe a day or two, been able to work out
and, and get the problem solved. That we always just keep talking about it, talking about it, talking about it until we get the final solution” (survivor).

Working problems out with one’s partner by talking about them helped to prevent potential relationship problems according to this survivor:

“…and that if she sees a problem with something I’ve done or, or work done, she will, she will, ah, she will bring it up. And so therefore we can discuss it. Because it is not good not discussing things and keep letting it eat at you” (survivor).

Good communication was also described as feeling close enough to one’s partner to confront and challenge them, when relevant, in an effort to move beyond the situation and come to a resolution:

“….Communication. Uh, knowing, telling each other when each other’s wrong. And, who ever’s wrong we talk about it, we try to straighten it out” (survivor).

One respondent felt that he and his partner shared comparable perspectives on a multitude of areas which they readily and openly discussed with each other. He attributed these factors to reinforcing the strength of their intimate relationship:

“…well, we have a lot of similar taste in things and a lot of similarities, and, communication is a big part of it. We’re both open about things and communicate freely with each other, and, that helps out a lot” (survivor).

(Partners)

Many partners said that good communication with their partners was vital to keeping their relationships as vibrant and meaningful as possible. Many partners, like survivors, cited positive communication as a key factor in maintaining intimacy although the two groups’ perspectives diverged somewhat from each other. As a whole, partners did not perceive their communication to be improved as much as more vigilantly monitored to enable the highest potential interactions. Some partners expressed how critical it was for them to feel as if they could regain some
semblance of “normalcy” into their relationships through meaningful communication. Some partners felt that the effort to maintain some level of communication between themselves and their partners was worth the shared sense of intimacy it facilitated, albeit, vastly different from their pre-TBI relationships. Some respondents shared that an important feature for them that strengthens their intimacy was being able to talk to their partners about difficult things, such as the challenges they confront as a result of having a TBI. This was true for couples who were together before and after TBI. One partner expressed how talking to her boyfriend about life changes and challenges was a significant factor in helping to strengthen their intimacy:

“…I think it’s a reminder to him how things have changed and we talk through that… I don’t think we would have a healthy relationship if we didn’t talk about those things” (partner).

Another partner disclosed how she and her loved one used to fight daily but that their communication improved significantly since his injury. She attributed the fact that her communication with her spouse was improved to three factors which included his refrain from risky behaviors since injury, having more time to spend time with each other, and her own patience with the process of superimposing a “new” reality of intimacy to such a magnitude as to alter almost every aspect of their relationship. The impact her pre-TBI relationship had on the re-construction of a post-TBI relationship was very pronounced for this particular respondent due to her and her partner’s admittance of pre-TBI marital problems. However, she shared that she believed a combination of having a supportive family, having children and having the desire from both partners to re-commit to the relationship helped to keep their relationship afloat through these challenges.

“…We make decisions together… We used to fight every day…. since this injury, it’s taught me patience and, you know, talk things over, because I was used to being in charge of everything. I’d just make all the decisions… We talk about everything now…” (partner).
ii. Positive pre-TBI relationship/Long-term commitment

(Survivors)

Most of the survivors whose relationships preceded their TBI shared that having a strong commitment to each other before their injuries contributed to being better able to manage the stresses that emerged due to the challenges of TBI. Some described feeling comfortable, supported or understood by their partners before their injuries which they felt helped to ease the challenges of living with TBI. Some participants acknowledged how difficult it would be to confront such challenges without a previous committed bond:

“I think it was a blessing that we had a strong enough foundation established with each other that when this accident happened it didn’t break us, in fact, we actually grew stronger as a couple over this last year…” (survivor).

(Partners)

Among couples whose intimate relationships preceded the TBI there was a common thread of having a strong sense of commitment to the intimate relationship and significant partner. Changes were more readily accepted, it seemed, if there was solid pre-injury intimacy among couples. Some participants shared that their previous respect and trust for their partners facilitated the energy needed to re-build or re-gain equilibrium in their relationships. These ideas are expressed by the following responses from some of the uninjured partners:

“I think that M. and I have huge respect for each other. Um, there’s nothing that I can’t tell M. And, before the accident, I’m not saying that he would be judgmental now, but, I know that I can go to M. with anything, and, we would sit and we would talk, and you know, we trust each other, we trust each other, we respect each other, and…we’ve always been very honest with each other. So, yeah, I think the respect, and, that plays a big part in a relationship” (partner).

One participant expressed that she and her spouse shared a close friendship and healthy intimacy prior to his injury and she attributed this to helping keep their relationship loving after his accident:
“Um, I think it’s the fact that we were good friends before all of this. We didn’t have any marital difficulty, you know, we weren’t in trouble before the accident” (partner).

Another partner expressed that he had too much of a history with his fiancé before her brain injury to just walk away just because things may have become more challenging or difficult:

“…people keep telling me I’m a good man because I’m still with her. I’m like, ‘What do you mean by that’? They say that most guys would be pretty much out the door…I just feel like I’ve got way too much with her. I mean, it’s just not something you walk away from…I mean, after all these years, it was a pretty serious accident but, you just can’t ‘Well, ok, she’s in a wheelchair now, time to go’, I mean” (partner).

The sense that partners relied on pre-injury commitment to get them through tough times after injury is echoed by this partner:

“It’s so different in so many ways. You know, we just have to work on it all the time. But, you know what it is; it’s probably our true love for each other and our commitment. I have to be honest with you, I think because there’s a commitment there and a willingness to work together” (partner).

One partner felt that her relationship was strong due to the fact that she and her loved one felt very comfortable with each other, built on years of being together.

“…we’ve been together so long, we know each other extremely well. We feel comfortable around each other” (partner).

iii. Spirituality

(Survivors)

Spirituality was expressed as a factor in nurturing intimacy, according to a few survivors. For them, sharing a deep sense of religious faith or spirituality served as a bond effective enough to withstand catastrophic or life-altering events such as TBI. Some participants shared how they believed their spirituality or religious faith helped to keep their intimate relationships from buckling under the stress of TBI and kept their bond to each other intact:

“I would have to say our relationship with Christ, with Jesus and with our faith…We firmly believed that when we got married there was a braid that was formed, me, S. and
God that can never come apart. I think that was the glue that bound us together” (survivor).

“Um, God” (survivor)[in responding to what he thought helped to keep his intimate relationship strong since his TBI].

(Partners)
One partner indicated that his spiritual life with his spouse was one of the major contributors to their strength as a couple. His conviction was so strong that he referred to their union as having a religious purpose and, in fact, was the whole purpose he was born as he describes here:

“I believe that I was meant for A. and was born to marry A. And, I believe that’s my purpose in life…I think the factor is God” (partner).

Interestingly, spirituality, in another sense, served as a source of support or as an outlet for an uninjured partner who pursued religious activities without her loved one:

“Since all this, I’ve become very active in a church. M. is not part of that church. But it is a big part of my life…I put aside some of that time to be part of the church, part of the organization. And I think that’s an outlet for me….” (partner).

b. Strength themes unique to survivors

i. Grateful to be alive

Many of the survivors expressed feeling grateful to have survived their injuries and shared that they had an overall positive attitude about life. This idea was expressed by this respondent:

“And, really and truly, though, it does make you appreciate life that much more, God, and taking each day as it comes, you know” (survivor)?

One respondent likened being alive to a supernatural or spiritual occurrence:

“It was a miracle I survived, it’s a miracle, a lucky miracle. You know that saying, ‘I’d rather be lucky than good’? I was lucky” (survivor).
ii. Partner’s characteristics fostering intimacy

All of the survivors, regardless of whether their relationships preceded or followed their TBI, identified particular traits in their partners that bolstered intimacy. These traits included their partners’ support, understanding, unconditional love and their willingness to stay with them or “stick it out” in “good times and bad”. “Sticking it out” included providing daily tangible support like managing the household, taking care of children and working additional hours to compensate for survivors’ physical or emotional limitations.

(1). Partner “Like a rock”—a constant, an anchor

When the participants were asked to share what they believed were the factors that contributed to the strength of their intimate relationships several people identified feeling supported by their partners as a critical component. In fact, survivors talked about feeling like their partners were a constant, or an anchor, or “like a rock” through their injuries and recovery periods. They felt that the fact that their partners stuck through the difficult journeys with them helped them get through their ordeals. They expressed how their partners contributed to their overall sense of well-being by making them feel loved unconditionally. The following comments from some survivors reflect these ideas:

“I think it’s knowing that no matter what it is I were to bring to her that it’s ok. It’s a, uh, it’s kind of like a rock, you know? It’s someone you can always count on” (survivor).

“Just the fact that she was always there behind me that she was there, that somebody was there, you know, her” (survivor).

(2). Partner sticking with them; “in good times and bad”

Some survivors specifically felt that the fact that their partners stayed with them after their injuries deepened their sense of reverence and gratitude towards their partners:

“Oh, she’s a miracle too. I am so lucky that she’s around for this. It’s amazing. You know, a lot of partners leave when this happens and, uh, she stuck it out through thick and thin. And,
she’s getting nothing I return, you know. There was no million dollar law suit or anything else. That’s it, it’s just us. So, she stuck around” (survivor).

“She’s strong. She stuck with me” (survivor).

(3). **Partner keeping it all together**

Appreciation for one’s partner’s ability and willingness to manage and keep their family running while this survivor was recovering in rehabilitation was noted as a demonstration of love and commitment to him:

“Um, for my wife, uh, it was a traumatic experience to go through. Something I can’t really relate to ‘cause I pretty much checked out when it happened. I definitely appreciate how she held the family together while I was …gone” (survivor).

(4). **Partner as mentor, nurturer or teacher**

Some survivors shared that they appreciated the way their partners mentored as a way of nurturing or caring for them as a “teacher” or “mentor”:

“She’s the beautifulist woman in the world to me. You know, uh, she’s teaching me how to, she’s my teacher. She’s teaching me how to read and write also, you know. Now she’s trying to teach me how to cook again. You know, she’s the best woman in the world for me. I would do anything in the world for R.” (survivor).

“The way she take care of me, like cook, clean. Just give me my attention I need and just like, I mean, you know, the way, just, the way she just is, the way she take care, the way she makes me feel, you know? Like none other. Like no one ever done that before” (survivor).

(5). **Partner understanding**

Another characteristic that survivor’s admired in their partners was their ability to understand and have patience when confronted with changes that emerged since their TBI:

“…and, she said, ‘Next time, it will be better next time’, that’s the way she is. She has understanding I can’t do it like I used to do” (survivor).

“That he’s always been there for me, um, he’s quite understanding of my situation. Just that he’s been very comfortable, he’s been very strong-helpful with my recovery and everything as far as what happened” (survivor).
iii. Having children together

Survivors also expressed that having children together was a source of strength and helped to motivate partners to stay committed for the welfare of their children:

“We both are totally committed to each other and we both love each other very much, and, especially since we have a child and one on the way that’s even more of a reason to make sure it stays that way” (survivor).

c. Strength themes unique to uninjured partners

Uninjured partners identified three factors they felt helped to buffer their relationships against the many stressors associated with their loved ones’ TBI. They are the following:

i. Feeling accepted and loved by partner

Uninjured partners expressed similar views in that they valued a sense of unconditional love and commitment from their partners. The expression of unconditional love was critical to intimacy as was reflected in the following responses:

“So if I’m delivering bad news or news that isn’t the easiest to deliver I feel really comfortable delivering it because he accepts me for who I am regardless of what I say or how poorly it comes out and I think that is really healthy” (partner).

“Well, I get all kinds of, she supports me the things I do. She loves me no matter what I do, so..” (partner).

ii. Receiving reassurance of partner’s love

Interestingly, some uninjured partners, specifically, one’s in which the relationship preceded their partner’s TBI, expressed that it was critical for them to feel that their significant others loved and appreciated them. This was heard from women participants who, in spite of the traumatic nature of their partner’s injuries voiced a strong need for their partners to tell them they loved and appreciated them for them to feel that the relationship was worth the struggle that sometimes existed because of issues related to the TBI.
Some respondents shared that their partner’s TBI resulted in a fundamental change in the amount and quality of how their loved one’s expressed their devotion and love and this resulted in frustration and at times, made them question whether they could emotionally continue the effort to re-build their partnerships. Receiving affirmation of love from their partners helped to confirm that their relationships were strong.

“It’s that moment he can tell me he loves me”.

“I find satisfying that M. tells me, and he makes sure that he tells me every single day that he loves me, every day. There is not a day that goes by that he doesn’t say, ‘I love you’, or ‘I love you and thank you for taking care of me’, or, ‘Thank you for sticking by me’” (partner).

iii. Supportive family

Some participants credited their families for gathering around and helping with whatever was needed, especially when one partner first sustained TBI. Some uninjured partners described the support, through practical and emotional bolstering, from their immediate families was a significant help in decreasing stress, fatigue, and overall anxiety. Some partners claimed they wouldn’t have been able to “make it” without their families’ involvement. Some people described their families as vigilantly standing by or jumping in and being there for support and assistance, as needed:

“His family rallied around. There was always somebody here…His mom would come for weeks at a time…” (partner).

iv. Professional Health-care background as helping to accept change

Some of the partners were health professionals who attributed their ability to accept their loved ones changes to their professional experiences and knowledge of brain injury. It was suggested that the general public knowledge of TBI is lacking and those partners without knowledge of TBI, or at least a general medical background were at a disadvantage because TBI
is complex and adjustment is a dynamic long-term process. One physical therapist who was also the wife of a survivor had this to say of having previous knowledge of brain injury:

“…like with my husband, because of his brain injury he doesn’t have the ability, like if he’s out in public like at a restaurant he might be talking to the waitress and because he’s so friendly and outgoing it could be perceived as being flirtatious…he just doesn’t have the frontal lobe brakes to stop or to know what’s appropriate and what’s not…sometimes he lacks the inhibition. But, because I know that, you know, I think it’s saved us a lot of arguments” (partner).

One partner who was an RN, discussed how her understanding of brain injury was a mixed blessing when her husband sustained his TBI:

“…I think sometimes being that I was a nurse was a blessing but on the other side, it was not a blessing ‘cause I knew ultimately the outcome was gonna’ be. You just, your brain is injured, so fundamentally it’s gonna’ change” partner).

Some partners who were health-care professionals expressed their concern for the majority of couples who experience TBI since there is so little understanding about it:

“God thankful Lord, I did have some perceptions of what was gonna go on and what was going on because I think that a person then if they have to learn all of that then still has to deal with all the difficulties…” (partner).

As described, there were many factors that contributed to relationship strength in spite of the impact of TBI. However, many respondents also identified experiencing specific losses and changes and ultimately, reconstruction, on both individual and relationship levels. These issues that are described within the next theme both challenged and in many instances, bolstered the integrity of participants’ relationships.

4. **Loss and Reconstruction**

Many of the survivors and uninjured partners related how they experienced loss and reconstruction following their TBI experience. A pattern emerged for many of the respondents that consisted of an acknowledgment of loss and then reinterpretation of how one viewed oneself and one’s intimate relationship following injury.
Specific losses or changes after TBI were, for the most part, similar for survivors and uninjured partners. For example, most participants expressed experiencing loss of friendships or social connections and professional and educational pursuits. Additionally, some of the survivors spoke about how their day to day routines and roles were diminished or absent since their injuries. Ironically, uninjured partners felt that they took on additional roles and routines as a result of their loved ones’ injuries, addressed in detail in a previous section. Reconstruction seemed to be more complex for uninjured partners because they often expressed grappling with a conscious coming to terms with reinventing their lives with a changed mate who may or may not have good recollection of what their intimate relationship was like prior to their injuries, whereas partners did not share such memory lapses. Some partners described experiencing their own dramatic “metamorphosis” since their loved one’s TBI. This process often involved negotiating their “new” loved one and making a choice to “go forward”-and re-commit to their “new” relationship and loved one, in spite of challenges and living with a partner who was vastly changed in many ways. Survivors, on the other hand, were more likely to report that they had changed for the better, or when they did acknowledge changes in their abilities, felt that they were not insurmountable and did not place their intimacy in jeopardy. For instance, changes identified by the majority of survivors were conceptualized as physical or cognitive changes that they did not perceive as changing their personalities or ways that they related to their partners in significant ways. Sub-themes from loss and reconstruction will now be discussed in further detail, examining survivors’ responses followed by uninjured partners’ responses.
a. **Loss**

   i. **Loss of Friends**

*(Survivors)*

Dwindling or lost friendships was a common complaint from most survivors after their TBI. There was an overall sense that the situation post-TBI was too difficult for their friends to handle due to cognitive and/or physical changes associated with their injuries. A survivor describes this scenario in this way:

“…there’s an amount of people that were real close to me that I considered close friends that…if I saw them on the street they’d say hello but they’d never ever pick up the phone and call me or come over…I really think they just don’t know how to handle it…” (survivor).

Another survivor explained that his physical changes were too challenging for his friends to deal with:

“…and, then, I got another buddy, I come home from the hospital and my face was bruised up, my arms slinged and everything else, and he just couldn’t look at me and I haven’t seen him since. And, two buddies, crying in the hospital that they just couldn’t handled it and I haven’t heard from them since” (survivor)

*(Uninjured Partners)*

Uninjured partners also often related a loss of friendships or social supports as a result of their loved one’s brain injury. They explained how their social interactions became very sparse due to a combination of not having as much in common with their friends as well as not having enough time or energy to devote to friendships after their TBI experience. Additionally, some partners felt that injury-related lack of social skills of their loved ones made it difficult for them, as a couple, to socialize as they might have previously. For instance, one partner had this to say about her loved one since his TBI:

“… he is not as social as he used to be. So that sometimes leaves you a little bit lonely when you’re not maybe going out and visiting people like you used to” (partner).
ii. Professional or educational goals

(Survivors)

Most of the survivors were not employed at the time of this study, although all of them had been working or attending school prior to their TBI. Some participants were working part-time or reported that they were hoping to return to work in the near future. One survivor initially returned to his job but the cognitive demands were too great and he eventually resigned and found a less cognitively challenging job. He explains the difficulties that he experienced with work after his injury:

“…a balancer for a commodities firm…so it’s a very specialized job involving a lot of money and everything…a lot of pressure, stress…” (survivor).

A couple of survivors both had teaching careers prior to their TBI. They described their disappointment in being unable to continue their teaching. One woman was planning on returning to work after staying home with her young child, when she had her accident.

“…it was so sad, when I had the accident…I used to be a teacher. And I was gonna go back, ‘cause my son, he had just started the first grade and I was gonna go back and that’s when I had the accident…” (survivor).

Another young woman had just started her teaching career and explained her initial disbelief that she could not resume her career:

“….I mean, everything I wanted to do I could do and then when this accident happened it was a major blow because it was like, ‘Wait a second. What do you mean I can’t do what I did before and I, you mean I can’t operate a classroom anymore…” (survivor).

(Uninjured partners)

The majority of partners were working full or at least part-time at the time of this study. For the most part, partners expressed loss of free time or relaxation due to taking on additional responsibilities at home besides their regular jobs, as was described in detail in a previous
section. Some respondents, however, lamented the loss of potential or actual careers or educational pursuits because they had to care for their loved one. For example, one partner described how she had to give up her goal of getting her teaching degree in to meet financial and other day to day obligations after her husband sustained a TBI:

“...I was getting my Master’s degree in, going back to school, so, um, I’m kind of heart broken that I couldn’t complete it” (partner).

iii. Roles and routines

Some survivors expressed a loss of daily routines since their injuries. They reported various physical and cognitive limitations that contributed to their inability to maintain or establish roles or routines and many had difficulty filling the void. Some respondents felt that this issue contributed to tension with their partners. A disruption in one’s roles since injury is perceived by one survivor as not knowing how to fill the void:

“Ok, before my injury I always had a whole lot to do. I always had something going on and something to do but, now, it’s like I slowed down…and don’t have hardly, anything too much of anything to do…compared to what I used to do” (survivor).

b. Reconstruction

Survivors and partners differed in the way in which they discussed changes in both the self and in the intimate relationship subsequent to their TBI experience. Survivors’ accounts tended to be less ambivalent and more positive. In fact, many felt, overall, that their changes were for the better and had had a positive impact on their intimate relationship. Some survivors also acknowledged a point of realizing that things would ultimately be different and they expressed acceptance, for the most part, of the changes. Uninjured partners tended to focus the process involved in coming to terms with their “new” relationship and making the best of it in an effort to move forward. Inherent in this process was the act of resigning to change and consciously deciding to accept the changes and go forward from there.
i. Change for the Better

(Survivors)

The majority of survivors related that they had made positive changes since their TBI such as learning to compensate for their limitations. One survivor believed his resourcefulness and strength contributed an added benefit of being pleasing to his spouse as he describes:

“It was concentration 24 hours a day seven days a week in almost everything, just to get back to where I wanted to be. Because I knew I had this brain injury. Well, what do you do? You get over it... You have to go around. ...and other people did notice it too. ...So, that was actually attractive to my wife, how strong willed I was and how I can do it” (survivor).

Another survivor felt that since his TBI he was more attentive and sensitive to his partner’s needs:

“I think that I’m actually better. Just because I’m more considerate and, I’m more, a lot of I know that TBI is... it really interferes with awareness, it may affect me as far as awareness, but, with this, I think I’m more aware of hurting her feelings, or trying to keep things positive or... keep things going in the right direction” (survivor).

ii. “Moving on”/Acceptance of changes

(Survivors)

Most of the survivors reported experiencing a process of resignation or acceptance of the changes in themselves and their intimate relationships since their TBI. Being cognizant of this, they felt, was helpful in re-establishing their priorities and life direction:

“Things have gotten a lot better. Things will never be like they were before the accident. That’s just the nature of the injuries. You’re never gonna be back to 100% again, and if you can come to terms with that you can deal with that on a little bit better basis. Your expectations aren’t so high” (survivor).

Another survivor described the futility in focusing on how things were before one’s injury. She related how changing one’s priorities contributed to her feeling more satisfied, in general:
“...if you dwell on it it drives you crazy. And there’s absolutely nothing you can do about it so
it’s time to move on...You just have to go on to, you know, the next level...you have to be more
attentive to different things You just have to change the way that you think. Some of the stuff
you may not like but it has to be done” (survivor).

(Partners)

iii. Acceptance of change/resignation of “new” relationship

Accepting changes seemed like a more complicated issue from the uninjured partners’
perspectives. The complexity for partners often was the result of their tendency to recall their
loved one and the intimate relationship prior to injury, whereas, survivors did not always
perceive how significant things were changed due to memory deficits resulting from TBI.
Although some of the partners said they understood changes to be an inevitable consequence of
their loved ones TBI they did not necessarily perceive these changes in as positive a fashion as
some of the survivors described them. In fact, many partners related how they consciously chose
to not disclose to their loved ones how significantly their relationships were changed, in an
attempt to not hurt the feelings of their loved ones. As a result, some of the survivors expressed
that they perceived their partners as being satisfied with their intimate relationships, although, in
truth, partners revealed that they often went through a process of consciously deciding to move
on and accept their “new” relationships and avoiding upsetting their loved ones with the reality
of how vastly changes were. Partners often had to confront their loved ones behavior and
cognitive changes that created many challenges and stress within the relationship.

Several partners related how some changes acutely after injury were some of the most
challenging ones to come to terms with and move on from there. There appeared to be a phase
that was characterized by sudden, negative changes that partners felt unprepared and unequipped
to deal with:
“…I mean the first year after the accident, B. didn’t want anything to do with any of us. It was really hard to bring him back to us, to make him part of the unit, the family, to bring him up to pace…When he came home it was pretty scary” (partner)

Another spouse recounted the initial difficult phases when her husband first came home making that time a most vulnerable one for both partners:

“…And intimately, that person is changing constantly, as he heals, as he’s working with the rehab people at first he was an angry patient and then he got that changed. He’s not angry anymore. He wanted to fight out of the box. He knew something was different and he just was trying desperately to be the same person he was. And he verbally was abusive at times. ..I think it was more difficult in the beginning…and, I think that if anything is gonna happen between a marriage, it seems like it would happen in the beginning, because at this point, we’ve leveled off …” (partner).

When children were involved partners often cited increased stress caused by survivors’ unexpected behavioral outbursts:

“…it’s really a rollercoaster. He had a lot of behavior problems…the problem was after we came home. Ah, he became a monster. Ah, I was in, in danger. My daughter was in danger…He was really quite aggressive in the beginning…It was difficult to stop liking him because I knew it wasn’t him. I knew that the brain was doing all these things…” (partner).

It seemed that partners had to make a conscious decision to integrate fundamental changes brought about by TBI in order to maintain or re-establish the integrity of their intimate relationships. This is expressed in the following excerpt from one uninjured wife:

“… the relationship has changed…. He used to grill outside every weekend. He does nothing like that….., it’s just a change in his perceptions of what has to be done, his ability to have enough energy to do the things that would be normal activity at home…. Deep down I had to learn with being accepting to also be less judgmental of the fact that he can’t do the things that we used to do…, I just had to take these changes and learn to live with them a little bit and still accept him … I’m not willing to give up, nor will I”. (partner)

One partner talked about being able to learn strategies to get her loved one to communicate with or engage in intimacy with her by “bribing” him:

“…when I met him, um, I just felt very free and very loved by him, uh, always showing his love. And after the injury, uh, that stopped for over a year. Uh, and I thought that I would never get
that back again, um, but we did. We did get that back, but it took a lot of hard work on my part, um, doing a lot of bribing. I had to bribe him to have intimacy” (partner).

Similarly, another spouse shared that she needed to persuade her husband to open up to her in order to close the emotional gap she felt. She found that he needed guidance to act more like an intimate partner again:

“…Tell him how I feel, and what would work for me. I try to guide him as how to handle a situation. I tell him I have needs, you know I say, ‘A wife needs to be hugged’. No, really, ‘Can you hug me?’ ‘You love the dog more than you love me’ [laughing]. (partner)

Some partners felt that being able or willing to accept change and be flexible or accepting of the give and take that existed contributed to strengthening or sustaining intimacy. This characteristic seems particularly salient for couples experiencing TBI because of the often profound changes they deal with on multiple levels. This partner had this to say about how compromise helped to buffer intimacy:

“…it’s what are you willing to do for each other, what are you willing to change for each other, um, and just the, the closeness that a marriage should have, um, also be willing sometimes to just let things go…willing to make life work…” (partner).

Inherent in her and other people’s stories was a struggle with how to negotiate relinquishing or shifting the balance of deeply entrenched roles or behaviors while simultaneously, trying to embrace a largely uncharted and unfamiliar, but not an altogether unwelcome relationship. Many of the partners expressed how this experience was a highly disconcerting but important one to come to terms with in order to ultimately move on and accept change. One wife conceptualized her spouse’s gradual re-emergence of his former self that helped her with the process of accepting her circumstances:

“…I don’t get depressed about it. I just move on and try to interpret my life in a different way now…the body is just like a little shell that we have, but the true self of who you are, I feel that it’s in the brain. In C. brain, I can see his little pieces coming back. The little bits and pieces that he was. They’re coming back, not everything, but I can see it…I see him in bits and pieces”. (partner)
Several partners spoke about how different their intimate relationships were presently as compared to before their loved one’s injury. A conscious decision to “not dwell” on the things that they missed in their relationship before injury and to “choose to go forward” seemed to be a prerequisite to acceptance:

“…we have a very good relationship now. Uh, it’s not like it was before, but it’s, at least it’s, it’s there and I feel that it is solid, and I feel that part of our love that we used to have for each other is still there…” (partner).

A process of resignation involving coming to terms with one’s new situation or significant other as a result of injuries was a theme that resonated with many of the partners. Some respondents described a conscious process of accepting significant and permanent behavioral, emotional, intellectual and physical changes in one’s intimate partner. Changes of such significance inevitably deeply impacted the intimate relationships of the participants in remarkable ways. There was a sense of being grateful to start a life again with one’s partner even though it was vastly different from their pre-injury relationship:

“It’s very strong because he feels that it’s very strong….and, if that’s all he can give me I’ll take that...And I will make our new relationship because I have a new life now. I’m not looking back…I have to be strong for myself, for my daughter, for my Mom…so, if he feels that we have a very strong relationship, it makes me ultimately happy that we do. Even though I know deep inside that it’s not what we used to have, but I choose not to dwell because I’m choosing to go forward” (partner).

There was an intense dedication by some partners to working through the challenges brought about by the TBI because of a strong pre-existing commitment to their significant other. This was articulated by one partner regarding the impact of her loved one’s TBI on their intimate relationship:

“I’m not willing to give this up. We had a beautiful um, loving relationship that’s why I fell in love with him. I fell in love with the man he was and it’ll never be the same again…” (partner).

The concept of “not giving up” the relationship was echoed by this partner as well:
“...and I think that if I wanted to let this marriage go, I probably would have a long time ago because of the struggles that we had because I’ve had to learn to accept some of the changes that’s going on. Um, I’m not willing to give up, nor will I” (partner).

iv. Personal Metamorphosis

Many of the partners described being significantly impacted by their loved ones TBI in ways that were both stressful and affirming. For instance, there was much agreement that the day to day additional responsibilities and stress from dealing with behavioral and cognitive changes contributed to chronic fatigue and anxiety in many cases, yet, there was also a degree of personal growth and self-respect for having “survived” and come to terms with such profound change. Some respondents realized their inner strength that they wouldn’t necessarily have confronted had they not had their TBI experience. One partner described how she experienced a total transformation after her spouse’s TBI:

“...I feel that if I learned anything from this whole experience, it’s that I’m personally in a different spiritual and mental stage. Um, I am not where my friends are, by far. I’m in a different stage and I feel that I am outside of myself at this point because I feel physically different myself. Even though it’s his disability, I feel that I feel differently. I don’t feel the way I used to feel” (partner).

One couple interviewed discussed how their profound metamorphosis transcended their relationship as a result of TBI. Both partners described their relationship as unstable and problematic prior to the TBI due to the survivor’s admitted long-standing drinking and anger issues:

“...before I got injured with the alcohol and other things happening, when she wanted to argue with me, I yelled a few words back...and I’d either go to a bar or go somewhere else and I ended up drinking” (survivor).
Tension and stress prior to this participants’ TBI transferred to another kind of stress for his partner, having to do with the sudden and profound change in the direction that their relationship was supposed to be going. This partner described it:

“…before this injury we were, actually that same week we were about to separate….we’ve lived so long with him being a certain way and now he’s a different way, and it’s take myself and the children to adapt to the new person and he got frustrated because he wanted things different right away because he didn’t realize the way he was before” (partner).

It is interesting to note that this partner reflected on the significant changes in their relationship after TBI that she attributed to her partner not drinking and being home more. In this respect, she was able to eventually come to see the relationship as better than prior to TBI:

“…he doesn’t want to go back to the way he was, you know, angry, yelling at the kids or anything…he want to go back to make us stronger so we can be more of a team…he’s the person I always wanted to be married to, I think” (partner).

The above reflections suggest a tension that some partners seem to be wrestling with between having come to terms with accepting fundamental changes and perhaps, loss of some aspects of their intimacy, while simultaneously, possessing a sense of responsibility or commitment to their loved ones, even though their relationships might be profoundly transformed. It was clear that most people were able to negotiate these disparate emotions but, not without struggles and ongoing effort.

5. **Attitudes and Media Constructions of TBI/Disability/Social and Interpersonal Attitudes**

Societal and popular culture attitudes and stereotypes or assumptions about TBI had an impact on participants’ sense of themselves as intimate partners as well as within their relationships, both positively and negatively. Overwhelmingly, respondents felt as though the general public embraced a very limited and stereotypical view of TBI. This created a sort of chasm from other people that in one sense, alienated them from others, but, in another sense,
offered an opportunity to educate people about brain injury, thereby, breaking down misguided notions of TBI, and, disability, in general.

Many respondents experienced reactions from others that included being ignored, stared at, patronized or generally misunderstood. Both survivor and partner groups perceived some or all of these behaviors from people familiar to them, such as friends and family, as well as strangers or acquaintances. Although both survivor and partner groups reported a noticeable difference in the way they were treated by familiar and unfamiliar people since TBI, their specific experiences were slightly different for each group and therefore, are discussed separately, with survivor responses preceding partner responses, in keeping with the format of this chapter. However, media constructions of TBI and ways in which people thought about people with TBI were fairly consistent across groups and are discussed together.

a. Survivors interpersonal attitudes

i. Ignored, Stared at or Patronized

Some survivors conveyed feeling “invisible” or irrelevant after their injuries. Many respondents described feeling as if people familiar to them prior to their injuries withdrew emotionally or physically as if they didn’t know how to relate to them after their TBI. Some survivors felt that they somehow were not regarded as worthwhile as they were prior to their injuries. There was a sense of being cast aside or being considered diminished in association with their changed status as “disabled”:

“…Uh, it’s like, when you got a disability, you’re not no help, no good to nobody…no more. Your friends move away, I mean, don’t want to be bothered with you, don’t want to push you in the wheelchair…they don’t want to help you when you get disabled” (survivor).

Some survivors felt that their friends, co-workers or acquaintances behaved awkwardly towards them since injury, in which they tended to either act overly, albeit, superficially, friendly
or abandoned them altogether. This respondent explains how he felt when out in public or when reuniting with old friends after his TBI:

“…most of the time, it’s …different…some people try to be overly friendly a lot of the time…and, then there’s a bunch of them who knew how I was before…Personally, they can’t deal with seeing me the way I am now” (survivor).

The sense of being alienated from others was not only associated with people known to participants but the general public as well. One survivor explained that most people tended to treat him in one of three stereotypic ways, namely, avoiding, staring at or patronizing him. He described his typical encounters in the following passage:

“…I go out in public and typically, one of two things happen. Either they completely ignore you and pretend like you’re not there or they stare. Or, three things,… people try to be overly helpful. They don’t want to let you do anything for yourself…everyone wants to come and baby you and I’m like ‘I’m not an infant’” (survivor).

ii. Abilities Underestimated

The general public’s unawareness of TBI seemed to result in survivors’ abilities or unique contributions to be underestimated. One survivor was hesitant to disclose his disability for fear that it would thwart his efforts to accomplish his goals. He supported the notion that other respondents expressed regarding current society not understanding disabilities:

“I want to know that what I accomplish is because of me and what I can do not necessarily what I might not be able to do or what problems I have, you know, as far as anything, you know, even as far as the population has come and understanding disabilities they still don’t have a clue. And, I don’t want my, I don’t necessarily want my disability to affect the opportunities that I do or don’t get, if that makes sense” (survivor).

Another survivor felt that his co-workers responded differently to him and perceived him as potentially not able to handle his job because of the knowledge that he had a brain injury. He felt that the connotations of having a TBI carried with it images of being deficient or damaged. It felt to him as if the stigma of disability preceded his actual abilities.
“…Because word has obviously spread around that I’ve had a brain injury so that classification of brain injury, everybody will look at you like something is going to come out of your mouth, weird and that’s because you’re, you’ve got a brain injury…” (survivor).

b. Partners’ interpersonal attitudes

i. Avoidance

Some partners expressed a feeling that people tended to either avoid or communicate with them superficially, in terms of their relationship with a loved one who sustained a TBI. One partner in particular reported that she thought it was strange how most people avoided finding out how she and her partner were doing or what was going on between them. She found it curious that no one asked questions that might be asked more freely had she been dating a man without a disability:

“I think that people who don’t know me well so neighbors or people who I see casually, most people are not up front with me. None of them will ask me ‘Why am with D., or who is he, or how did we meet’? Most people won’t ask which I find is really interesting” (partner).

ii. Misunderstanding

A general lack of understanding about TBI by friends, family and the majority of society, at large, was, for most of the partners, a significant challenge. Many respondents admitted that the dearth of TBI knowledge contributed to feeling alone and unsupported. Some felt that they were forced into situations in which they felt the need to defend themselves or their partners. One respondent expressed her dismay about people not having a grasp of TBI:

“…, there’s no education out there and people don’t know how to respond to brain injured people…” (partner).

Many people, according to some respondents, seem unable to relate to brain injury survivors because of the cognitive and behavioral difficulties that often accompany their injuries.

“There are many many people that do not understand mentally challenged people and so they become very critical or they are afraid. They don’t know what to say to them” (partner).
Some partners felt as if they needed to justify to their family and friends why they chose to have an intimate relationship with a TBI survivor. In particular, one participant described how her family assumed that her motives for dating her boyfriend stemmed from her need to fulfill a “caregiver” role as if there could be no other explanation for being with someone with a disability:

“I think that people who don’t have experience with people with disabilities, with brain injuries, it’s hard for someone to understand why someone would be attracted to someone with a disability….Some of the members of my family are concerned that I’m involved in this relationship with someone and the attraction is more because I could be in a care-giving role with this person versus that I’ve met this person who is actually a nice compliment to who I am that I feel that I have a really healthy relationship with and it’s not the care-giving piece is the attraction” (partner).

This same partner also confronted stereotypes that prompted confusion from others about her relationship when out in public. It seemed that stereotypes about people with disabilities crossed personal and public domains. She describes some of the reactions of people this way:

“We were out at a concert and it was anywhere from people were confused about why I was out with D. I’m assuming he’s in a wheelchair, I don’t really know why based on the looks that we got, or someone would pull him aside and ask him what I was doing with him…We’ve gone out to eat and waiters will ask me what he wants to eat rather than asking him what he wants to eat so I think there’s definitely some unfortunate stereotypes about people with disabilities that I think I’m a lot more aware of…” (partner).

Likewise, some partners expressed challenges they confronted when out in retail stores with their loved ones. People’s reactions to survivors’ behavioral outbursts or cognitive limitations were difficult for some partners as often one’s good intentions were actually not helpful or relevant to the situation. One partner explains the frustration and dismay she felt when dealing with salespersons’ and other shoppers’ bewilderment and alarm at her husband’s behaviors:

“Ah, people would look at him funny in the store because they thought, he was, he looked suspicious, because he would look up and then pick his nail and stay in one position, staring at something. So, it was really heart-breaking that people would want to assist me when he would be going into those little rages that he would yell at me…And people would come up to me,
‘Honey, I should call the police for you, right’? And I was like, ‘No, thank you. Mind your own business. We’re ok’…Can’t they see that I’m not asking for help and I’m smiling and I have a smile on my face? That should give them a clue. If I’m smiling and I’m not saying please help me get the police. That means I’m trying to deal with my situation and you should respect that. And the majority of people did not….I think its pretty pathetic” (partner).

iii. Exploitation

Another partner expressed anger about how some people exploited his wife after her injury.

“…One time I came home and there were 2 nosy ladies in our house and M. was in her nightgown. It was 9:00 at night. It was a silly premise. They took advantage of the fact that she was not aware that she could have told them to go home” (partner).

Additionally, he shared how other people’s erroneous ideas of brain injury contributed to harmful communication with his children:

“At church some people told my children that their mother was going to be a vegetable and they were very impressionable at the time. I don’t know how people can be so cruel” (partner).

iv. Opportunity to Advocate/Educate

On the other hand, these situations were also considered to be an opportunity to educate people and to ultimately dismantle stereotypes about people with disabilities.

“…I’m hoping that if people out in public can see how comfortable it is, than maybe they can, I don’t know, learn something in the process or it would break some of their stereotypes” (partner).

One partner stressed that if people had more opportunities to interact with survivors they would understand on a deeper level and there would be more support based on this understanding. She relates an experience she had with her sister-in-law who initially didn’t understand how challenging things had become since her husband’s TBI:

“It really takes them living with the person, or for example, my husband’s sister finally came out and stayed a couple of days so she could see things that were different…and then she was more supportive…” (partner).
(Survivors and Partners)

c. Media Portrayals

i. Negative and Dis-Empowering

There was general agreement among both survivor and partner groups that the media contributed to people’s negative or fictional understanding of TBI. Some of the survivors described their experiences with the media as contributing to society’s idea that people with brain injuries are completely helpless or have a mental illness. This survivor talked about his experience:

“…it’s infuriating, the media, TV, books, whatever, entertainment, they tend to intentionally or unintentionally portray people with a TBI as being severely deficient as in less than a normal person. They’re literally disabled to the point where they have to have help all the time…” (survivor).

Other survivors agreed that media constructions of people with brain injuries were disrespectful and unrepresentative of the reality of the situation. There were descriptions of portrayals of people with TBI as being “dumb” and lacking intellectual capacity. The following response captures these ideas:

“…they’re portrayed as kind of, idiots, basically. Their brain has been injured so, therefore, the entire person has been injured frame of reference from the media portrayals. But, your brain is a very strange and strong thing. You can be injured and it can affect one aspect of your life, but it doesn’t necessarily affect every aspect” (survivor).

The erroneous association between TBI and mental illness portrayed in popular culture discourse like the news was noted as a common and harmful representation to some:

“…they kind of dumb us down a little bit. ..especially the news, you know, ‘Oh, so and so, he was just released from T.P. mental hospital…’ he might have been there for fighting alcoholism or he he got a knock on the head…now he’s burnt a church down…but the media puts things together that don’t necessarily go together. That kind of boils my blood” (survivor).
A couple of partners also expressed dismay regarding the media’s construction of TBI. The realities and complexities of brain injury were believed to not be fully conceptualized, if at all, in the media. This partner put it this way:

“…you can understand from the movies that the public is not very understanding….I don’t think that you really get an impact of what reality is about or what really these people are facing…” (partner).

Similarly, another partner expressed how she believed that media representations often resorted to sensationalized views of brain injury focusing on the horror of the actual injury with no follow up of survival or recovery:

“…seems like they show the worst of it in the media. Some lady fell off the roof, how gruesome the crime was, …” (partner).

Other respondents recounted memories of TV or movie portrayals of people with head injuries as severely injured and passive:

“…the majority of time people are in comas… (survivor).

ii. Timely: Exposure due to Iraq War

There was identification of one positive contribution provided by the press in their coverage of soldiers returning from Iraq with head injuries. Some respondents noted that this coverage was helping to increase public awareness of TBI as this response indicates:

“…on the actual news they’re starting to talk a lot more about how TBI is the main concern from the war, so that’s at least brought attention to it and I think that’s great that the attention’s being gained…because of how the guys are acquiring them with being in the war” (survivor).

d. Personal attitudes of TBI

Survivors tended to express a sense of community and increased understanding based on their own experiences with TBI whereas, partners described feeling more compassion or empathy as a result of their experiences. However, there was a general consensus that their personal
experiences with TBI helped them become more in tune with people with disabilities and more understanding of the process one might have.

(Survivors)

i. Sense of community

   Both groups unanimously felt that their personal experiences with TBI contributed to their deeper understanding and compassion for brain injury survivors and their partners. Some expressed a feeling of “community” with other survivors. Survivors, in particular, described how their own injuries made them feel closer to others with TBI.

   “…it didn’t really affect us because nobody in our families or any of our friends, nobody was really disabled…And, when you become part of it your attitude towards it changes so much,…you can do it more gracefully because you’re part of the group…you’re one of the people…” (Survivor).

   A few other survivors agreed that identification with other people with TBI occurred after their injuries:

   “I think being around in rehab with people with the different degrees of injuries, I can relate to them more. I guess it goes back to the same kind of thing. You don’t know what it is like until it happens to you” (survivor).

   Personally experiencing TBI was key to expanding awareness and understanding as this survivor expressed:

   “Granted they get a little bit different because you understand it a little bit better, because, now in a sense, know what’s going on better because you’re dealing with it to an extent yourself” (survivor).

(Partners)

ii. More understanding/Enlightenment

   Uninjured partners also communicated that their TBI experience gave them more insight into circumstances others with disabilities might experience as well. Some partners shared that their sensitivity to how society treats disabled people was sharpened after their own experiences:
“I think I have a much better understanding of what the person with a disability goes through and how long the coping process takes…and I have a much different view of how the general public sees and treats people with disabilities…it’s different if you’re out on a date with that person or loading their wheelchair in and out of your car. It’s just totally different” (partner).

This partner supported the idea of gaining more insight from his own disability experience:

“Probably changed in the fact that you get to see firsthand, what they are really going through…” (partner).

iii. Fuller appreciation of the complexities of disability

The challenges of negotiating simultaneous but not necessarily compatible roles as a partner to a TBI survivor was thought to be more fully appreciated by many of the partners because of their own experiences. The consensus was that their own experiences provided a deeper understanding of the complexities of being an intimate partner of a survivor. This partner expresses this idea:

“…And, I think I have a lot more empathy for significant others of people with brain injury. I think I have a much better understanding of how difficult it can be for them to balance just all the dimensions of a relationship with having to be a wife or a girlfriend and care-giver…” (partner).

In essence, the overwhelming response from the participants was that misperceptions were at least partly attributable to faulty or a lack of representation of traumatic brain injury in the media. Survivors and partners also expressed how these constructions of TBI negatively impacted their sense of self and their intimate relationships. Their personal experiences with TBI were helpful to counteract these images and to provide increased understanding.

6. Healthcare and Health Care Professionals

From the preceding themes survivors and partners revealed a complex array of both challenges and positive factors affecting intimacy after TBI. There were many common issues among respondents and, in several instances they emerged following the initial stages when
couples are more likely to have minimal or no way to formally receive support or assistance from the current healthcare system.

We were interested in exploring what participants’ experiences with healthcare and professionals were and their thoughts about potential services and supports that would be helpful after the acute phase and long-term. This last theme from the initial interviews is divided into 3 sections. The first section addresses issues/aspects that were lacking in current healthcare. The second section is concerned with positive aspects that participants experienced that were affirming to their experiences. The last section details responses to questions concerning recommended services and characteristics of professionals that both groups felt were important to improving or establishing interventions aimed at supporting intimacy. In keeping with the rest of this chapter, survivors’ responses precede partners’.

Healthcare

a. Areas for Improvement

Survivors and Partners:

i. Lack of intimacy services

One of the most agreed upon issue, according to all the participants, was the lack of any type of intimacy or relationship services or supports following TBI. In fact, both survivors and partners reported that intimacy was generally not addressed at all during any phase along the health care continuum unless participants initiated issues related to intimate relationships or sexuality. Even then, the information was limited and medically oriented and not focused on intimacy or sexuality.

“…They had me see a psychiatrist once a week…and that never came up…mostly it was to ask, ‘How do you feel about your accident?’ That’s all they ask you about. They don’t ask about ‘Who else is in your life?’ ‘What’s going on with that?’” (survivor).
Even emotional issues seemed to be lacking for some survivors during their interactions with psychiatric professionals.

“We had a psychiatrist but he was more interested in how I took tests and my memory but not so much my emotional stats and how fragile I was emotionally. Physically, I was improving…but, emotionally, I was kind of stasis…I feel that if you are provided and you’re made to work on it then you will find that energy”. (survivor)

Other survivors felt that resources regarding intimacy or relationships were sparse, if addressed at all:

”Yeah, nobody ever did a thing…I had to find these things out on my own. There were basically no services about the relationship issues” (survivor)

There was no recollection of this topic ever being addressed:

“Um, I don’t believe it was ever addressed, Ever, during rehab or post” (survivor)

“I don’t recall any help from the rehab center when it came to my sexual behavior whatsoever” (survivor)

Partners also lamented the lack of information they received regarding relationships and intimacy. There was a feeling among many partners that they were unprepared to know what to do or how to relate to their loved ones within an intimate context.

“Nothing was there…. I mean there’s got to be something, something more available…But there is very little in terms of relationships and what a person and a couple might need to, you know, be prepared for” (partner)

Some partners suggested that because they were in a more rural area services may have been sparser. Perhaps this also contributed to the lack of services but it was unanimous among all participants that no services were available regardless if they were in urban or rural settings.

“…it may be partially the area that we’re in but, no, we haven’t had any services or had any offered…it’s more of a rural type area…a pretty good sized area and there’s a good college there but it still seems like there’s not much support services…” (partner).
All in all, participants reported not having any supports or services for intimacy. Some people specifically pointed to this research as being the only source of formal intimacy support. When asked if there were any supports or services that was helpful in terms of being in a relationship this partner responded:

“No, the answer is no. Which is why it’s a good thing that they’re having this research right here” (partner).

ii. Inadequate involvement or supports for partners and families

It was interesting to note that not only did participants relate that there were no intimacy supports, in general, but, they specifically felt that the lack of support for the significant uninjured partners was detrimental to the health of both partners. Similar to the preceding sub-theme this issue was also expressed by both survivors and partners. Some survivors perceived their partners’ issues regarding intimacy as going unaddressed:

“…and I would talk to my wife so she was able to see but I don’t think that they had anything to help her…” (survivor)

“…it would be nice if they had something going for the spouse of the husband…one of the counselors told me ‘When you’re in here you’re getting all the attention but your wife she’s on the outside she gets nothing. And at first it really didn’t click with me. That this whole experience really rattled her too” (survivor)

Similarly, many partners believed that because they were usually the closest to their loved ones, physically and emotionally, it would have been beneficial if they were integrated into interventions directed solely for survivors. Some respondents felt that this lack of integration contributed to them being ill-prepared and unknowledgeable about how to approach their relationships after TBI. Some partners talked about having unmet needs that left them feeling abandoned in some ways. They sometimes expressed feeling as if professionals failed to tap into their unique resources:
“…and you can be sitting there crying your eyes out begging, saying, ‘This isn’t going to work, he’s not ready to come home’… nobody knows your partner better than you, because that is the intimacy part of it…The whole entire outpatient experience was horrible…because you are not a big part of it’” (partner)

Other partners specifically felt that there was a lack of focus on the entire family. Even when survivors were preparing to leave facilities to go home, several partners admitted that they did not have any family training to help prepare them for the next phase after inpatient hospitalization.

“…There was not a social worker there that I could even call to say, ‘You know, I have this concern’. I didn’t have any voice while I was there. Anyone that I could say, ‘Look, I’m running into a problem. Can you come and talk to see me’? … … I think there needs to be more of a focus on the family… even when he left there was no family teaching. Not at all… There’s nothing…” (partner)

One partner, a physical therapist, spoke about her own professional experience in working with patients with brain injuries. She reflected sentiments also expressed by others regarding not having enough emphasis on how the injury affects the entire family.

“I think that most of us spend a lot of time focusing on how the injury has impacted the individual but…we also need to be sure we’re spending enough time looking at the family unit as a whole and including how their injury has impacted their significant other and or family, kids, whoever is part of that piece” (partner).

Likewise, other participants felt that, in general, the professionals they dealt with failed to accommodate or reach out to families of survivors who were available in daytime hours because of other life commitments. They were dissatisfied with the lack of appreciation on professionals’ parts that most partners had conflicting responsibilities day to day and would be better served if there was something after hours, or at least, some type of outreach to the families who were unable to be present during the day.

“…Incorporating… the parents, spouses and partners… we lived in the city and I had to work and we have a small child at home. I wasn’t there all the time, and, it just felt like they weren’t reaching out to people like us”. (partner)
iii. Pursuing own search for intimacy supports

Because of the reported lack of services many respondents related how they attempted to seek information themselves. Some survivors spoke about desiring to understand more about changes in their sexuality and other related issues of intimacy but ultimately having to search for information on their own because of no formalized education.

“…nothing’s ever been offered. I had to go try to find these things out on my own. And, I just kind of never found out about it. I just tried to figure things out on my own and do them” (survivor).

Some partners specifically expressed apprehension regarding not knowing what to expect when their loved ones returned home. They expressed having to find things on their own after they realized that this type of resource was not offered.

“I just had to stretch out to find out what was going to be going on in terms of bringing him home and what I was going to be facing here at home…” (partner).

Another respondent told how she and her spouse sought out help for themselves and their family when they couldn’t find any assistance from their healthcare facilities or providers. The counseling they discovered was found through alternate means after the rehabilitation process.

“Oh, that was family counseling…We went when he went back to work, so, it was after a year. We did that on our own. I went through our insurance company to find it…” (partner).

iv. Lack of knowledge of TBI and intimacy

Several participants felt that most professionals they dealt with lacked in-depth knowledge about TBI, particularly the impact on relationships in the short term and, potential challenges in the future. As a result, the overall sentiment was that of feeling ill-prepared to handle potential behavioral, cognitive or emotional problems.
There was consensus that if professionals’ did not possess personal or professional experience with disabled people, specifically TBI survivors, or appreciation of partners’ commitment to one another then their ability to advise or guide couples would be limited as well. The following partner expressed this idea:

“…it would have been helpful if they were able to somehow put themselves in the shoes of the person with the disability, to be able to understand their side or their view as much as possible. Again, just maybe making themselves more educated or more knowledgeable about the aspects of brain injury” (partner).

Conceptualizing the multiple behavioral, cognitive and physical issues that potentially arise after TBI within the context of one’s personal relationships or family structure seemed to be an important factor in facilitating steps to helping couples to adjust to changes. Otherwise, there appeared to be discordance between professional and family goals and this negatively impacted the therapeutic relationship.

“…, I got so upset… I said ‘you don’t understand…I’ve been married for so many years. I can’t just let this go… if he doesn’t remember me now, he’ll never remember me again. He’ll never love me again… they have to be in more touch with the family members and really respect the dynamic of that family. If I choose not to institutionalize my husband, I think the professional has to do everything they can to respect that and help me achieve the goal of taking my loved one home” (partner).

b. **Helpful professionals/Services**

Even though participants reported a lack of formal support for intimacy there were several accounts of positive interactions with some professionals throughout the acute care and rehabilitation process. Thus, there were some factors that helped couples cope even if there weren’t specific formalized programs or supports for intimacy. The most predominant feature that survivors and partners identified as a positive factor in helping with their relationships was having the opportunity to talk in a counseling type situation, both, together and individually.
Most often, this was facilitated by a psychologist, physiatrist or social worker. The counseling was not specific to intimacy or relationships but more general. Intimacy issues were discussed if participants chose to disclose issues related to intimacy or sexuality.

i. **Providing forum to talk as couple**

Although not an ongoing program for participants in rehabilitation, even occasional opportunities to share issues as a couple were noted as useful, as was the case for this survivor:

“…and, there were a couple of times that my psychologist allowed both of us to come together and we were able to communicate my concerns and frustrations…so it was kind of like a couple’s counseling type of a thing and that was very beneficial” (survivor)

Other survivors also stated that counseling was helpful at the individual and couples level. He felt that counseling helped to improve the communication between him and his partner.

“Marriage counseling…It helped. We communicated with our counselor individually and then communicated together” (survivor).

Some partners shared that, although not proactive, when a counseling opportunity did present itself, it helped to defray challenges already present. It was expressed that problem-solving, via talking through issues served as an important source of support.

“…when we were going through a rough period we went to a psychologist who we met when we were at the Rehab. He was very helpful…” (partner)

ii. **Providing advice and information about resources**

Advice from professionals about to what to do about physical or emotional sequelae of TBI on sexuality and intimacy was considered helpful according to many of the survivors and partners. Some people also identified offering guidance towards potential resources as very helpful. This type of practical advice was considered to be extremely helpful. It is important to note, however, that it wasn’t necessarily standard practice to offer such advice, but, more likely to be at the discretion of the particular health professional.
The following couple, for instance, talked about how they were helped immensely, especially during their rehabilitation experience, by their rehab physician because she exuded genuine concern for the well-being of both partners and had a knowledge of potential resources to address their concerns.

“…I’m talking to her about these sexual things …So, she’s ‘Hey, don’t be shy, I heard everything before…’ And, so we talked …, ‘We should send you to a urologist and see if a prescription is necessary…’. So that was pretty cool. If I had any hang ups I can call and leave a message… …she made it pretty easy…” (survivor).

“…She was our support. She is our rock, she is a wonderful physician…She has supported us and helped us through so many things and had led us to the right direction, to get us on that path…if you’re not pointed in the right direction you’ll never find that avenue” (partner).

Other respondents recounted positive encounters with their social worker who counseled one or both partners about potential scenarios that might emerge to impact their intimacy in the future. Some partners specifically noted these interactions as critical in impacting the ways in which they actively sought to relate to their loved ones after TBI.

“…Z. said you might have to go deeper with your relationship emotionally look at everything like that. And I have found that’s true. So, I have to be willing to open up…” (partner)

Similarly, other partners credited a healthcare provider in advising them how critical it was to play the role of their loved ones advocate for the overall welfare of their partnership. This advice, as well as the others was representative of professionals who demonstrated insight and knowledge of TBI and relationships. In addition, professionals who exhibited compassion and offered additional time, beyond the standard allotment of care to facilitate a dialogue about concerns and questions signified especially helpful attributes.
“…and I was breaking down and I talked to the psychologist…she helped me through a lot of things, a lot of feelings. And she told me, ‘You’re going to have to stand up’. ‘You’re going to have to stand up and voice your opinion. And you’re going to have to be C. voice’…(partner)

Sometimes, respondents recalled a caregiver who provided advice or support that was not of the general thinking of the other team members and this unique perspective served as a catalyst towards providing confidence and hope that things would get easier and better between partners.

“…and the psychologist told me that the best thing to do was to give C. time, the time that everybody told me not to give him” (partner)

7. Recommendations

Survivors and partners agreed, in general, about the types of supports and resources that they felt were needed to improve the current care of people with TBI and their partners concerning intimate relationships. The main recommendations included professionals taking more of an active role in addressing and initiating intimacy and sexuality issues so that people felt more at ease and supported around these topics. Other recommendations were for health care professionals to increase their knowledge of TBI, and their exposure to TBI survivors and partners so that there could be greater appreciation for the dynamic process of adjustment and recovery. Counseling with a particular focus on intimacy and relationships was stressed as a critical component to TBI rehabilitation. Within the counseling domain, many respondents expressed a need to educate both partners about stages of TBI and potential factors to anticipate that could affect relationships. TBI support groups were also proposed as a vital element to assist couples in confronting challenges, problem-solve solutions and to serve as a forum to share personal experiences. Other recommendations included longer term supports such as ongoing counseling and transitional places to practice skills to becoming an intimate couple again. Lastly, more research like this current project was suggested
to provide additional opportunities for people with TBI and their partners to share their stories and, in so doing, develop mechanisms to enhance their intimate relationships.

i. Professionals need to take initiative to address intimacy

Although there were definite positive instances and characteristics of some professionals, the main feeling among respondents was that in most or all cases, the survivor or partner had to take the initiative to receive the support they needed.

Some survivors felt that although it was awkward, in many cases, to have to bring up sexuality or intimacy issues, it was necessary in order to obtain the information they sought.

“Um, you have to ask all these questions, because nobody’s gonna volunteer any of this information about intimacy. ‘Are things functioning physically for you’? ‘What’s different than before’? Because everybody’s shy…” (survivor)

Many of the partners, too, agreed that professionals needed to take the initiative in providing information and guidance about intimate relationships. It isn’t good practice according to many participants, to take a passive position and wait for survivors or their family members to raise questions about intimacy. The risk with this tactic is that issues will be improperly addressed or not addressed at all.

“…sexuality is such a gray area as far as who brings it up and I think that some of the patients are comfortable enough to bring it up to their therapists or their physicians, but, I think it’s something as therapists and doctors and psychologists that we need to be more proactive in bringing up because there’s a lot of things in healthcare that if you don’t ask they’re not going to tell” (partner)

Other partners also agreed that intimacy and sexuality issues need to be formally addressed by professionals because there is a certain naivety on the part of survivors and partners about the fact that these issues are even important in the early stages after injury. Some partners argued for professionals to take a proactive approach in the treatment of intimacy after TBI for the long-term well-being of both partners.
“… Even if the patient may be a little shy or doesn’t feel that they want to really talk about it. it’s something that needs to be addressed, because…. You need that support….and I think that if you can get that support early on, I think that makes a big difference…It really does need to be addressed….” (partner)

   ii. **Professionals to increase knowledge base of TBI**

   Often, participants suggested that professionals might address intimacy issues after TBI more comprehensively and consistently if they were better trained and knowledgeable in this area. Several respondents, in fact, reported that they perceived some apprehension and awkwardness on the part of some professionals when questions or concerns related to intimacy or sexuality arose. Respondents, on the whole, felt that although there was a plethora of knowledge about the physical aspects of TBI, understanding of interpersonal relationship issues lagged significantly behind. Many participants also suspected that healthcare providers had limited experience with TBI survivors or families many years after initial injury and this contributed to the gap in their knowledge and subsequent inadequate supports and services, especially long-term and beyond the scope of physical or cognitive functioning.

   “…if they are able to somehow put themselves in the shoes of the person with the disability…. …making themselves more educated or more knowledgeable about the aspects of brain injury. (partner)

   iii. **Intimacy counseling for couples**

   Although many of the respondents recalled instances in which they participated in counseling sessions with psychologists or social workers the primary emphasis of the counseling was not on their intimate relationships. If the topic of intimacy emerged, it was usually because one or both partners brought up an issue related to it and then, it might be addressed as a result. In other words, intimacy was not addressed proactively, rather it was addressed in response to an individual’s or couple’s inquiries. Some of the survivors spoke about the difficulty articulating
problems of intimacy because of its personal nature and cognitive or language difficulties.

However, it was stressed that talking about issues in a counseling environment would be very beneficial for the well-being of both partners.

“…There are certain things that become problems of the intimacy that brain injured people just kind of back off from where I really think they should talk more to express themselves. I really think that counseling for people would help if they could get involved in that…” (survivor)

Some survivors expressed a desire for intimacy counseling as a tool to inform them of their partner’s perspectives so that they could more readily address any relationship issues and resolve them for the goal of improving their intimacy.

“…I would like to know how my wife feels so we can work on it so…it’s not necessarily talk. She’s standing back…” (survivor)

Providing survivors with some insight about their partner’s experiences would have been helpful in contributing to increasing empathy and understanding of one’s partners’ challenges.

“…it would have been nice to know that your wife has been through a traumatic incident also and she’d been holding down the fort for the past 6 months. Oh, if they would have given you the other side of the coin. You went through a traumatic injury but your partner went through a traumatic experience too…” (survivor)

Most partners, too, felt that intimacy counseling was vital for the health of their relationships and their sense of selves as intimate beings. There were many unknowns for couples regarding how TBI would currently affect their relationship and how it would impact it in the future. Since these issues were not addressed in any formal or consistent fashion in the existing healthcare arena, there was a call to integrate this type of counseling and education into TBI rehabilitation. Counseling partners about sexual and intimate functioning after TBI was suggested in order to more fully understand how their significant others’ injuries are or may impact their relationships. In this way, several respondents felt that they would have been more prepared to expect different stages.
“Well, there should be counseling for couples… I’m sure the brain has something to do with the sexual thought process. So, I don’t know if the brain healed itself…I would like to know. That would help in the counseling if I would have known is this going to go on forever…?” (partner).

Other partners also expressed a need for counseling that would be attentive to one’s emotional needs as well as to educate about cognitive and behavioral functioning and abilities of survivors in terms of intimacy. The dearth of information about sexuality and relationships was troubling to many partners and a definite area of need along the continuum, not just the acute stages of TBI.

“…, it would be nice to have someone to talk to you … ‘Are you feeling lonely’?, ‘Is it working out for you?’ or, you know, ‘Can you bribe your spouse to help with the relationship, what could you do?’ I had no tip. Only what I read on my own… And there isn’t much sex on that. …I couldn’t find a lot on, you know, getting back with your partner after a brain injury…my greatest concern was…his cognitive ability to be intimate with me… So I think that’s something that no one really talks about…and that was one thing that really kind of hung over me all the time…” (partner).

The lack of emotional support and counseling was also felt by other partners. They expressed frustration at the imbalance of services, with a tendency to provide support for the physical and cognitive functioning of the survivor, but, a palpable absence of support for the intimate partner. Also, the need for education about TBI was echoed as well.

“There needs to be help out there for understanding the different stages of brain injury and how the brain repairs itself and how TBI people react….Someone who can help put a family back together. Help establish the relationships. I mean, the doctors get them physically functioning, but there’s nothing done for the emotional side of it” (partner).

Limited participation in one’s loved one’s treatment programs was another area of concern, particularly, in terms of counseling and training. Focusing on the survivor without consciously including the partner in the process was problematic for some respondents.

“…They’re just focusing on him…And, there is no counseling, it’s only the patient counseling and if you come in to ask them for the other type of help that you need, cause you need an understanding of it…you need to be a part of it right from the beginning….when you’re
removed from it I think it’s a very negative thing…it is separating you even more…A tragic accident like this, is, I mean, it’s hard” (partner).

There were some topics that some partners felt would be more appropriate to talk about without the presence of their loved ones, such as changes, unmet sexual and intimacy needs, and so forth. Some partners made the point, as well, that some subjects were not comfortably discussed with family members or friends and sometimes, people had a limited support system in which to express their feelings.

“…definitely counseling for the partner who doesn’t have the traumatic brain injury. If they don’t have the family support what do they have, you know, who are they going to talk to? And, who will be there to answer their questions? And, sometimes you can’t talk to family members about some of the questions like that it’s hard to ask a family member to talk about it” (partner).

Lastly, there was a suggestion that counseling should resemble a class for partners to learn from each other strategies and stages that their loved ones were potentially experiencing that impacted their relationships.

“…I would have been inclined to have do some kind of networking of spouses, …It was what I needed. I think that the spouse could do more with a type of network that set up to go over and talk about what was happening in their lives, not just give me the ABC’s….Maybe a specific class on you as a spouse: ‘This is what you’re going to face, be facing and so let’s work at telling you what to expect and what I’ve heard from other people’ because with the classes that I did attend… they were not all about relationships” (partner)

iv. Support groups

Support groups for survivors, partners and both groups together were recommended by most of the participants as an important resource for intimacy. The advantage of groups specific to survivors or partners entailed being able to share experiences with people who were going through similar things in order to help each other. Some survivors cited the commonality among
other survivors that made support groups beneficial. Knowing that other people had similar experiences and being able to share those experiences was attractive to several of the survivors.

“I think if there were groups to go to, discussions-to have the time to sit with other people who were having the same problems, Just being able to love and help one another…I’m sure there are a lot of people with brain injuries and strokes and they don’t have a group to go talk to” (survivor).

The aspect of sharing similar experiences with the other survivors was also appealing to other participants as well.

“…They were groups where other head injured people would come to. And you realized then that you’re not alone. Or each group would bring up problems they were having and you could identify with it cause for sure, it was something that you’ve had trouble with it too…” (survivor).

The value of sharing similar experiences and learning from each other was also expressed by many partners as justification for participating in support groups. Support groups for other partners would create an environment where participants would feel comfortable disclosing their experiences, according to many partners.

“…group sessions that they can be able to learn more about their spouse, or their better half…be able to open up and talk in a group situation…because people are more open when they’re in a group situation that they can talk about people and…people that’s going through the same things that they’re going through…” (partner)

Some partners looked to the potential of support groups to serve a need to connect socially with other couples. The camaraderie of others in similar circumstances was felt to promote social connections that might otherwise be difficult to establish.

“…some sort of a support group for couples would be nice on a weekly or bi-weekly basis. Some type of group to get together and talk and to be able to meet other couples and go out and do things with other couples” (partner).

The emotional support that a group potentially offered was considered crucial for some partners. It was important to have a forum where one could feel comfortable expressing their
fears, frustrations and other emotions without burdening or upsetting their loved ones. One partner credited the support group she participated in with having other partners who were further along the process than she and her spouse were at the time and their experience helped her to cope with challenges she was having adjusting to her newly injured partner.

“…the brain injury support group that I started going to…it was magnificent…everybody kind of gave me the forum for me to have my little outburst…and they helped me through it…They told me to hang in there that it would get better. Look at them…they were doing better” (partner).

When asked whether people thought it was important to have separate groups according to gender, age or socio-economic or ethnic identity it was interesting to note that only a few respondents felt that these factors were significant. The majority of participants reported that specific characteristics were not relevant in terms of designing support groups, or any other supports, for that matter.

(1) Gender

One survivor and one partner respectively, both women, identified an interest in participating in a women’s support group. The following survivor felt that she would have more in common with women.

“…I would probably prefer a woman’s group because I think we have more in common…” (survivor).

One partner felt that there were gender specific frames of reference that would make a women’s support group more relevant personally.

“I think a support group for men and women. Just because men and women think differently. What you or I may think may not be the same thing as our significant other thinks…” (partner).
(2) **Age**

As with gender, there was only one survivor and one partner, respectively, in this case, both men, who believed that an age oriented support group would be beneficial. The survivor who felt that an age appropriate group was important was one of the youngest participants.

“Well, for younger people because their mind be racing and turned around. You might be thinking of one thing rather than the right way to think” (survivor)

The following statement was quoted by the oldest participant which suggests that age may be a factor only when the continuum leans towards very young or elderly when issues of age become more prevalent or significant. However, this partner also had the longest experience with TBI so that may also be a factor to consider.

“Well, most of the people are young people. I always wanted to get support groups for spouses because the issues are different. That’s why I like the support groups. It addresses some of the problems of married couples who are involved in brain injury” (partner)

(3) **Socioeconomic status**

Only one partner endorsed the importance of a socioeconomic specific support group. She also identified as a racial minority and there may be a correlation with more limited socioeconomic opportunities.

“Well, you’re gonna have different financial, what should I say, categories. You’re gonna have different neighborhood problems, so that’s why I say that…” (partner)

v. **Long-term network of support and TBI education**

Some partners, in recognition of the long-term issues and dynamic nature of TBI and intimacy, advocated for supports that were longitudinal. The need for psychological counseling and ongoing support throughout the continuum of care was emphasized by several partners so
that issues could be addressed as they emerged that were not necessarily apparent at the initial stages.

“… it would be helpful to have psychological support that’s set up … not just during the first six months but… over a continuum to meet not just with the person with head injury, but, also with the significant other…with some clients it’s difficult either because of their head injury they don’t have the cognitive processes to communicate the same way that they used to or just because of the communication patterns that they’ve gotten into in their relationship they need a mediator or someone to help everybody move forward. I think for sure this would be helpful…”

(partner)

Some partners pointed to the longitudinal nature of healing from TBI for both partners and because of this there needed to be supports in place to meet the long-term needs of couples.

“I just think that there should be counseling, couples counseling and I think it needs to come all through the whole healing process, from the time that they’re in ICU ‘til the time, years later…I think it’s kind of an ongoing thing, until the two people are satisfied with what they have…”

(partner)

Long term support was perceived by another partner as an actual physical structure or simulated “home” where entire families could go and practice interacting as a family again.

“…we need to have a transitional place …that the wife can stay with the husband if he is transitioning into some type of normaley where it looks like a home, … where the therapist would be and they would say…, ‘„he’s bursting out in anger. He’s breaking things’ and somebody would have been behind me whispering to me ‘This is what you do’ instead of my daughter being at home with me and hiding in the closet because he had a hallucination and he’s cutting up the sheets with a knife. … now I know it was a huge mistake to take him home. He wasn’t ready”

(partner)

vi. Provide research opportunities to share personal experiences

Many participants contributed unsolicited suggestions to create opportunities, through research and other venues that would allow survivors and partners to have a voice and express their stories. A lot of the respondents, in fact, shared that they rarely had the chance to speak about their experiences, and that, in and of itself, was therapeutic. Many participants were
grateful to be able to reflect on their relationships and their sense of themselves as intimate beings.

“I think what you’re doing right now is very helpful… just to, you know, to go back and reminisce on things that were good and bad with your relationships…” (survivor)

Partners, too, responded favorably to sharing their experiences and some even felt that being able to express their feelings led to emotional growth that extended to being a more reflective intimate partner.

“…TBI has made me face certain things about myself… growing as a sexual being… I’m coming to that point right now with our intimacy, which really makes me happy that I’m talking to you right now because I haven’t actually said that aloud” (partner)

B. Follow-Up Interviews

Follow-up interviews were instrumental in clarifying and expanding upon the major themes that emerged during initial interviews. Participants described what life was like over the 6 months following initial interviews, in terms of their intimate relationships and their sense of themselves as an intimate partner. Reflections regarding the impact of time on respondents’ experiences regarding barriers and strengths to intimacy as well as continued recommendations for healthcare services were instructive.

Factors that obstructed and supported intimacy reflective in initial interviews were, for the most part, significant as well during follow-up interviews. In this way, follow-up interviews contributed to supporting the major themes that emerged in the initial phase of this project. Learning to adapt to and accept significant changes in oneself, one’s partner and one’s intimate relationship, on the one hand, while deepening one’s conviction for the importance of long-term supports in establishing or restoring equilibrium in relationships characterized the essence of the follow-up phase for all the participants.
In keeping with the structure of the chapter, survivors’ responses precede partners’ responses but where relevant, the themes are discussed together when perspectives of both groups are similar. In addition, factors negatively impacting intimacy precede factors that support intimacy. Lastly, a description of participants’ perspectives about healthcare concludes this section.

1. **Factors continuing to negatively impact intimacy**

(Survivors)

Survivors expressed several areas that continued to challenge intimacy including not feeling as if they were living up to the standards they set for themselves, feeling guilty about their deficits, sensing a continued lack of trust from their partners, low expectations from others, and being emotionally detached from their partners.

a. **Not living up to their former selves**

Many of the survivors shared that they experienced a continued sense of guilt, shame or unworthiness about not being able to fulfill expected social and work roles. They described feeling a dissonance in terms of how they perceived they should be functioning as compared to their actual abilities. Some survivors contributed their sense of angst as stemming from deeply ingrained societal expectations. There was a gender specific component to feelings of guilt and inferiority generally associated with the men survivors. They admitted to feeling that something was wrong with them because they could not provide for their families as they should have or had been able to do, prior to their injuries. Some of the survivors talked about not living up to their expectations of being a “man”.

“…There’s this sort of pride of work…you should go to work and work overtime and come home and take care of your family…You get that pounded in from day one and now you’re changing the formula and that doesn’t go over so good sort of thing” (survivor).

Proving oneself was also associated with male gender roles:
“Some days, I think, ‘C’mon man, get in the car and drive to work and quit doing this’. …Crashing, there’s this sort of failure attached to it that wears heavy on my heart, you know? I have to prove to myself and everybody else that I can still do it” (survivor).

In some circumstances, Letting oneself and others down was also indicative of some of the women survivors. They talked about grieving their old selves because they still weren’t able to return to work or be the person they were prior to their injuries.

“…If your brain is injured you don’t work at the same level that you did…you’re exhausted at 7pm….that’s still hard because I was always the one that people called if they needed something…” (survivor)

b. Continued lack of trust by partner

Sometimes, survivors felt that their partners still not trust them or allow them to make decisions due to changes in cognitive or physical functioning. They expressed frustration at this and it affected how they related to their partners.

“It’s still going up and down emotionally. There are ups and downs with the wife. She urges me to do this and do that and always figuring out what’s the right and what’s the wrong way…I’ll say something to her but I have no authority…” (survivor)

c. Continued low expectations from others/Stereotypes

Some survivors were sensitive to reactions from others and felt that there was a strong bias towards associating head injury with incompetence. For instance, since initial interviews, this survivor returned to work and found that other people assumed he wasn’t competent because they knew about his brain injury.

“…they find out you had a head injury and they just look at you a little different. And I can pick up on that. They don’t say anything. Everyone tries to be prim and proper but I kind of understand what they’re thinking…” …this guy, he got a brain injury, I’m wondering …if he knows what he’s thinking, if he knows what he’s doing. How massive and how severe was the injury…” (survivor).
Some survivors also felt that even professionals displayed stereotypic or dismissive attitudes or assumptions that if one has a brain injury then they are either in denial or not competent to provide accurate information. When asked about others’ attitudes, respondents, overall, supported their initial feelings that healthcare professionals as well as the general public tended to make assumptions about them based on their TBI.

“As a patient when you bring something up to the people that are directly involved with it they write you off like ‘He had an injury, he’s not coming to terms with it’, ‘He’s just angry about being hurt’. Nobody takes you seriously and that just makes me angrier” (survivor).

d. Feeling alienated from partner’s life/Emotionally separated

Although this theme was unique to a couple of the survivors it was a significant one that continued to impact their relationship from initial through follow-up inquiry. One survivor, in particular, seemed to grieve the emotional distance she felt from her partner. She sustained a TBI at least 20 years prior to this project and she and her spouse had been together for longer with her TBI than without it. The unique struggles she and her partner experienced could have been attributable to this or to the dynamics of their relationship or both. It would be interesting to have perspectives from more couples who experienced TBI several years ago to further examine these issues. This survivor communicated a continuing sense of resignation that her spouse had a separate life from hers, emotionally and intellectually, and while she grieved this, she also expressed an acceptance of it as part of her injury.

“…it’s just that he has a life of his own that I’m not part of…When he goes to work…he’s with the people from work and I’m just not part of that. I can understand that because it’s just not part of my life anymore…” (survivor).

There was ambivalence because she also acknowledged that her partner, perhaps out of a sense of commitment also provided for her basic needs and this seemed to be the major thread of their relationship. Because she did receive some support from her spouse, in terms of practical
versus emotional support, she did not feel entirely justified in making a grievance about her partner’s pursuit of other women’s companionship. Since the initial interviews, there was a growing tension or ambivalence between understanding her partner’s need to seek others’ companionship and resentment and grief about not being the one that captured or met many of his emotional and intellectual needs.

“…He’s got a lady friend, which I’m sure he’s gotten real close to that I can’t handle it so when he goes I just don’t inquire about it…That’s his own life…And, I could file for divorce or he could file for divorce but…what the hell good would it do for either of us?…I just put up with an awful lot of what he does, but, he constantly takes me places, he’s my driver…you just have to respect what they want…you don’t want to hold anybody back…” (survivor).

Another survivor felt that he was drifting emotionally from his spouse over the last couple of months since the initial interview. He expressed how his resolve or his willingness to withstand the difficulties with his spouse and his ability to “roll with the punches” was disintegrating. His discontent was magnified because of the lack of any supports or resources to help him and his spouse work issues challenging their relationship since his TBI.

“Over the past couple of months things have been bothering me. I roll with the changes for the most part. I have not shut down emotionally, totally, but I’ve definitely toned down. I feel more isolated just dealing with my wife” (survivor).

(Partners)

Like survivors, most partners identified barriers to intimacy that was the same or similar in nature to those that they discussed during the initial interviews. However, partners tended to expand in greater depth about some issues as compared to survivors. For instance, partners emphasized their lack of appreciation, initially, for the lengthy process involved in their significant others’ efforts at regaining skills including their ability to express intimacy as they had done in the past that was affirming to their relationships. They questioned more than survivors did how their relationships would continue to evolve in the future in view of the significant changes to themselves and their mates. In addition, partners described how their
intimate relationships were not necessarily improved with time, but, rather, time was contributing to their learning process of how to accept and adapt to the likelihood of continuing profound and lasting changes in their loved ones, themselves and within their relationships. These themes are detailed in this section.

Several partners reported several challenges to intimacy persisting since initial interviews that included ineffective communication which often led them to feel more emotionally detached from their significant others. They also expressed having continued unmet needs and added responsibilities that left them feeling stressed and fatigued most of the time. In addition, many partners admitted that their social interactions were diminished or that they had to reconstruct the ways in which they socialized with friends or family to optimize their loved ones ability to participate. The majority of partners also shared a continuing struggle to balance intimate partner and caregiver roles. Feeling changed personally as well as learning how to love a partner who is fundamentally changed was discussed, as well, for partners with their mates prior to their TBI. Lastly, many partners communicated a feeling of uncertainty about what the future would hold for themselves and their loved ones. These issues are discussed in further detail.

e. Communication

Communication difficulties continued to frustrate some partners, even though they could intellectualize and rationalize that these challenges were attributable to their loved ones cognitive and behavioral changes. The additional effort it took to try and be understood by their mates was challenging in many instances.

“…I do feel like it’s a struggle to keep that communication a strength and sometimes it’s frustrating because I do feel like there are times we aren’t communicating well, that I’m not being understood and vice-versa…” (partner)
Some respondents were concerned about regaining the level of communication they previously had. They felt that their partners’ interactions with them were more shallow or superficial, and therefore, were less satisfying, overall.

“…I was lucky if I could get him to greet me with ‘Hello’ or ‘How was your day?’ There’s no, very little conversation between B. and I up to recently and it’s still very limited but it’s more normal now” (partner).

f. Unmet needs and increased responsibilities

Partners spoke about feeling a cumulative effect of taking on more responsibilities since their mates TBI that persisted from initial contact. Constantly trying to juggle day to day responsibilities in addition to their work was stressful and exhausting for many partners. Tasks that were previously shared with their mates were now thrust upon them and they expressed how this wore away at intimacy over time that produced chronic levels of fatigue.

“The difficult part is being the person who has to do everything and I’m so tired…It’s my exhaustion with everything that’s on my shoulders. I work full-time. I’m a teacher and very involved in my work…I love my career but it’s so overwhelming. I think that’s what takes away from having a really good intimate moment…” (partner)

Partners often reported that they felt increased stress and fatigue because all the daily responsibilities fell on their shoulders, whereas, prior to their partner’s TBI, tasks were shared between them. Many partners reported that it continued to be a challenge to have the energy or time to focus on their relationships when asked at follow-up.

“…fighting traffic and picking up the kids and getting home and…I’m the only driver…if I could say, ‘Hey, can you run to the store for me?’ But I can’t do that” (partner)

g. Decreased social interactions

Many partners affirmed their continuing sense of diminished friendships or social networks since their significant others’ TBI. The difference at follow-up was their perceptions of why this occurred. They felt that part of the reason included their mates’ cognitive or behavioral changes,
and their own increased fatigue and stress from increased responsibilities. Additionally, several partners also experienced a personal metamorphosis as a result of their partners’ changes, thus, transforming the way they related to others. As a result, some respondents expressed the importance of having at least one good friend to confide in especially as time went on.

“I only have one best friend and she’s as good as a family member…she’s a good sounding board for me. But, we’ve lost everybody else…” (partner).

With time, also, some partners attempted to come to terms with their diminished social interactions or friendships and to learn to adapt to the needs of their loved ones by modifying the ways they sought out social interactions, often at the sacrifice of their own needs or preferences.

“…I’ll tell you the one thing that has changed we don’t do a lot of social going out with other folks because… just, noise, and, I’ve heard this about other people that have had head injuries that’s just best to keep them on a one to one. You’re better off visiting one couple so our social life had kind of quieted down so we really don’t do the kinds of things in terms of a lot of social activities…that has changed and we’ve learned to adjust to that”. (partner)

h. *Balancing roles and regaining equilibrium*

The ongoing process of balancing intimate partner and caregiver or supporter continued to challenge many partners at follow up stage. Many partners, in fact, were astounded at how lengthy the process was to regain or establish equilibrium in their intimate relationships. They also questioned how long the process it might be that they would feel the need to negotiate between caregiver and intimate roles. This was an issue that emerged with couples who were together both before and after TBI. One partner shared how she was surprised by how long the process of “healing” took for the man she was dating, whom she met after his injury.

“…it’s just that it’s slow for the body to heal, it’s slow for somebody to figure out, ‘Ok, I’ve done this job for the majority of years…and what do I do now, with the talents that I have’, so, I think that it’s hard to figure out what my role is in trying to facilitate that other than just being supportive…some days it’s easier to be patient than others…I’m really surprised at how slow the whole process takes…” (partner).
Other partners supported feeling unprepared for how long adaptation and adjustment to TBI actually took. Even couples who were together for many years prior to TBI said they didn’t anticipate such a long process of sorting through issues that obstructed intimacy.

“…It’s unbelievable how much time and how long it takes. I never would have thought it. I thought, ‘Oh, let’s go and see someone and in a couple of months we’ll be back together…”” (partner).

i. Life altering changes

Many partners commented on how much their mates continue to be affected as a result of TBI and in turn, their loved ones ways they were affected impacted how they perceived themselves. According to several partners, the ways their significant others demonstrated changes was, not physically as much as behaviorally, emotionally and intellectually. These changes continued to affect their intimate partnerships in far-reaching ways as they expressed feeling as if they were with a completely different mate. Participants commented on the far-reaching changes that affected their partners, themselves and consequently the state of their relationships.

Some respondents seemed to have a more difficult time negotiating and accepting the changes. One partner found it very difficult to come to terms with the disconnect in his wife’s pre-TBI to her post-TBI functioning, so much that he reiterated these emotions in initial and follow-up interview. He and his partner were together the longest of the participants and, his loved one had sustained her TBI at least 20 years ago. He seemed to be struggling the most, in many respects, with accepting his significant others’ intellectual decline and emphasized these struggles in many of his responses to both initial and follow-up interview questions.

“…there’s a lot of things that she does that every once in a while I sit back and think she used to work for food stores and she used to take care of everybody else’s cash drawers and she was a very competent employee and now she’s a totally different person…It’s been a long time. I’ve been married to a disabled person longer than to a non-injured person” (partner)
Another spouse was also struggling with the current state of her loved one’s emotional and cognitive functioning. She seemed to not be able to embrace the “new” situation as well as some others may have and expressed a longing to have what she had prior to her partner’s TBI. This partner expressed her difficulty with the abruptness of the changes that she experienced, and like the previous partner, captured these themes throughout initial and follow up interviews. It appeared that some people were at higher risk for difficulties coping, perhaps due to pre-injury psychological issues and it would be beneficial to capture individuals or couples at risk in order to ensure more targeted services or support.

“…I really want back what I had. I know I’m not going to get it…we experienced so much there’s no way it can be back the way it was…what’s happened to us it caused us to change…Your whole life has changed…it’s like being married to a new person. Well he is new, he’s not the same. And, your relationship all of a sudden comes to a halt, it stops” (partner).

It was interesting to note that other partners, although also acknowledging significant changes and challenges to intimacy seemed better equipped emotionally to accept these changes and mobilize whatever resources, including pursuit of knowledge about brain injury, to try to ease the division between emotional instability and attempts at intimacy.

“…life goes on so what you have to do is keep walking and that’s what I try to tell him. Intimacy…there are changes. We’ve had major changes in our way we approach each other. It’s really hard to be soft and kind and patient and gentle with someone’s who’s depressed a lot. And, he loses his job how are you not going to be depressed…How can you be intimate with someone until you learn and understand and take that challenge of trying to just accept them for all the changes that have gone on in your life?” (partner)

Another partner related how her spouse’s ongoing feelings of inadequacy were a departure from his behaviors pre TBI. There was a lot of pressure in their relationship regarding her having to reassure her loved one that she loved and was still attracted to him as a “man”. She anticipated this issue would be a long-term challenge in their relationship.

“We still have issues and mostly it’s me trying to re-assure him…they feel less of a man because they’re not providing. That’s a big issue in our home. They feel less of a man because
the intimate part of it is not what it used to be…We definitely have that struggle and I think that’s a struggle we’re going to have from here on out because it doesn’t matter what I say” (partner).

Other partners shared their feelings about the profound personal changes that they continued to experience as a result of their mates TBI. Although this topic was introduced in initial interviews it seemed to be more prevalent during follow up interviews. Some partners described how every aspect of their lives was impacted and because of this, personal change was an inevitable outcome.

“…you play a different role, you become a different person. You just are not the same than prior to the accident…I don’t know if I could describe how different I am” (partner).

One partner who described her “metamorphosis” in initial interview felt that she was still proceeding through changes and that, since initial contact, she was at a more peaceful, spiritual place with her changed self and relationship.

“…and I reached, not a plateau, but, I’m at a place where I’m at peace with myself and I keep evolving with that and feel very spiritual….” (partner)

j. Uncertain future

Because of the challenges to intimacy that tended to beleaguer partners it was not surprising to hear them express uncertainty about how the future would continue to impact them personally and within their relationships.

Reestablishing an equal “adult” relationship was an ongoing challenge for some partners because they related feeling as if they were emotionally and intellectually at odds with their partners.

“…I’ve disconnected myself somewhat. ...I’m not giving up but it is what it is and let’s see where it goes….” (partner)
Since initial interviews, some couples were able to arrange to participate in counseling to work out these and other issues but some partners expressed skepticism that their relationships would improve.

“…the lack of passion still troubles me…That’s a primary focus of our marriage counseling, to get more on an equal level. It’s not there yet. I don’t know if it’s ever going to be there…” (partner).

Several partners questioned what life was going to be like, on a broad spectrum, in the future for themselves and their significant others. They feared that this process and the unknowns were sometimes difficult to accept. There was an awareness that time would most probably bring significant change but also that the timing of TBI adjustment and recovery was uncertain. This had an impact in terms of having difficulty planning or anticipating as couples, without having to factor disability into the equation might not have had to do.

“…I would not like us to be in the same place say a year from now…all these unknowns, when will things change, where is the end of the road going to lead us to? So, I think that’s frustrating for him” (partner).

There was an acknowledgement by many partners that living with TBI meant that one must live day to day and not necessarily know how things were going to turn out. This was a process that partners seemed to be coming to terms with since initial interview.

“…we don’t know what the future holds. We don’t know what tomorrow’s going to bring. It’s just an everyday experience…” (partner).

Other partners described how the first years after their mates’ TBI were most unstable and difficult to live through because of the changes that the survivor is still going through, and because, partners are at their most vulnerable, not being experienced with the process. There was a leveling off, according to some respondents, after 2-3 years following injury and even after this time, there was some uncertainty about how things would be.
“…he’s been injured 3 years, nothing’s going to change. We are where we’re at. So, our relationship has matured to the point where I think it will always be where we’re at… along… the first year was just probably the worse and after that leveled off and we were better… you’ve got to be a strong person that’s going to really work through it because the changes still came and up until the two years he really was a very different person. ..There was a lot of drastic changes up and down and over and out… so, you have to be patient and just see where it’s going to level off” (partner).

k. Aging with TBI

One partner mentioned potential problems that could occur during the process of aging with a TBI. His significant other, in her 60’s, was beginning to demonstrate secondary disabilities such as balance and orthopedic problems that may have been aggravated by overall decreased activity from her TBI. This issue would be useful to explore in greater detail as the population is aging and more people will be living older with a TBI.

“…She’s getting more, she’s falling more lately. She’s having more problems with balance. Sometimes she stays home and says her knees are bothering her so her weight and her age and disability all combine I think to cause problems with her knees…” (partner).

2. Factors continuing to bolster intimacy

In spite of the challenges to intimacy described in the preceding section both survivors and partners reported they were feeling more positive about their intimate relationships since initial interviews. For the most part, positive aspects were similar for both groups although there was a distinct difference in some instances and these are described where relevant.

Characteristics that continued to strengthen intimacy, according to survivors, included a sense of commitment to their partners, good communication, physical or cognitive improvements and acceptance of changes. In addition, some survivors were emphatic that their participation in individual counseling was paramount in increasing their awareness and developing strategies to improve dysfunctional communication patterns in order to be a more loving partner.
Partners agreed that a deep sense of commitment, good communication, making an effort to address dysfunctional communication or behavioral styles, partly through counseling contributed to strengthening their relationships. In addition, some partners felt that spending more time together and having a supportive family was important.

a. **Commitment**

Feeling committed to each other was illustrated with an acknowledgment that the relationships were not without their challenges. The key component, according to several survivors, was a willingness to keep working together and relying on the history of their mutual dedication to each other.

“…it’s all about working together and I don’t think you can really work together without a strong bond…the desire or the commitment to strengthen that bond” (survivor).

In fact, some survivors felt that because they had been together for so long with their partners they were able to get through difficult times after TBI.

“I think it’s truer than ever. I think if we didn’t have the history there we wouldn’t have made it…” (survivor).

Partners, too, acknowledged that their commitment was a sort of lifeline to hold them together when there were times that it was tempting to let go instead because of the challenges of TBI on their relationship.

“…it has been strained but we are plugging along with it… I can tell you that there’s times when it would be so easy just to say, ‘This is too much, you know I can’t do it’, but, boy would you lose if you did that I think” (partner).

It was interesting to note that even with couples who were not together until after TBI there was an acknowledgement that the bond or friendship that developed between partners was too valuable to lose even amidst day to day challenges.
“Oh, I do say that it’s on the upswing and we acknowledge friendship which is even better cause as we know friends are valuable and we sort of want to keep each other on our good list” (partner).

b. Improved behavioral, physical or cognitive skills

A few survivors attributed their improved physical status with helping to make their intimate relationships better over time. There was an implication that once their physical status was better they were more desirable or accessible to being intimate. Notably, the following response came from a survivor who, initially, expressed her inability to give her significant other a “real hug” or “a real kiss”. In follow-up interviews, this same survivor again focused on the physical aspects as significant to intimacy.

“…it’s been easier being able to be hugged and not being a problem to him…” (survivor)

c. Communication

Many of the participants reported that, since initial interviews, they had been trying to make an effort to communicate more effectively with their significant others. For instance, some people talked about making time for each other to talk or to try to problem solve day to day problems together. Some respondents also shared that they tried to improve dysfunctional communication patterns through individual and couples counseling. For instance, one survivor described how he was learning to be a more respectful partner by allowing his significant other talk first and by doing more listening.

“Uh, lately, it’s been better because I’m letting her speak first. I’m listening more than I talk. It’s not always 100%...I’d say it’s 90% better…” (survivor).

Some partners described how they learned, through experience, to facilitate discussions as normally as possible, even when their loved ones were not necessarily capable of sustaining or comprehending everything that was being communicated at the time.

“Because I continue to talk and communicate with him like a regular adult” (partner).
There was a feeling that many partners were becoming more adept at knowing how to promote the most optimal response or reaction from their loved one and, as a result, tended to have less arguments or misunderstandings than previously.

“…We’re still arguing but it’s so much better. It’s still really frustrating but I’m learning how to cope. But, she has a disability and she has to realize that and I have to realize that and so when I get frustrated because she doesn’t do what I ask her to do it’s like, ‘Ok, wait a minute. She probably doesn’t remember what I asked her to do’, and it’s a lot on me to say, ‘This person can’t do this, so don’t get upset, don’t yell at her’ (partner).

Some partners expressed how they were conscious about not upsetting or worrying their mates and, thus, structured their communication in a way to avoid topics or issues that they might not be able to emotionally handle at this point. They continued to strengthen their ability to modify situations or communication in order to get the best response from their mates.

“…I will say to him things like encourage him as he’s going out the door to do this new job. When he gets home I try to sit and listen to him talk about this new job. I encourage him to talk about it. ..I don’t think we talk specifically about how our life has changed. He may tend to dwell on things if we did that” (partner).

d. Counseling

Some survivors reported that they had been participating in ongoing counseling since initial interviews and that this was helping to address behavioral or emotional issues from their TBI that they felt contributed to more positive communication within their relationships. Having an opportunity to talk about issues with professionals who facilitated increased insight into maladaptive behaviors was beneficial to one’s intimate relationship.

“I’m going to counseling right now…I used to snap off for any reason…for little stuff like that. But, she taught me how to be calm and listen. I have a tendency to talk before R. asks her question…I have a tendency of speaking first, whatever I say goes…which I don’t really mean it because she’s the only person that I really love. I don’t want to chance myself on losing her…To lose three years of love it doesn’t make any sense. I learned to be calm and collected…” (survivor).
One survivor felt that his involvement in counseling since initial interview was contributing to his feeling more confident and accepting of himself since his injury. If participants were engaged in counseling it was generally because individuals sought them out and took the initiative to seek these services, versus being a standard part of rehabilitation.

“…just getting that reinforcement every week. ‘What happened this week’? and I tell her the good things that happened and I tell her the bad things that happened that week. But, I always come out of there feeling like superman…I can do anything…” (survivor).

Some partners reported that they were grateful for the effort that their significant others made in trying to improve the ways they interacted, through counseling. They reported feeling more encouraged because their loved one was trying to work on the relationship by addressing some of the behavioral issues that were causing tension.

“…He wants to be more positive and I think he draws from that and it’s ok, maybe I’m called to help somebody so I’m just patient and I know that he is really trying, because he’s really making an effort. He does go to counseling…I can see even in the way he interacts with me he’s more considerate” (partner).

One partner credited family and individual counseling as significantly improving her relationship. She felt that she and her loved one were doing better from initial interviews, in large part, because of the extent of individual and couples counseling they were involved in.

“A lot of support. This had changed a lot from the initial interview. First of all she’s better. We’re in family counseling. She and I are in individual therapy. I’m in individual therapy. …” (partner).

e. **Acceptance of changes**

Many survivors shared a sense of increased insight from initial interviews regarding accepting changes and changing priorities as a result of their TBI. They expressed coming to terms with the fact that they were dramatically changed and acknowledged that life would be permanently altered for them because of their injuries.
“…I have a disability, there’s no changing that. I’ve been through a lot so accept that. There is another life outside of a disability. Life don’t stop because you have a disability…it’s more of a challenge but there’s no life ending. It’s just a challenge…It took time and patience and therapy to understand that, but, I love what I had to go through because it made me a stronger person. It made me a wiser person” (survivor).

Change was also expressed in terms of appreciating progress from initial injury and making an emotional shift to seeing the positive factors in their situations, more than they were necessarily able or willing to do initially.

“…and, you think about how was it 2 years ago and…what’s different now? And, you can see progress so that pushes you for more progress and realizing the glass really is half full so we’re on the way” (survivor).

As in initial interviews, changes were perceived in a more complex context for most partners as compared to survivors. All the partners described their day to day experiences as more or less trying to “survive” and re-interpreting their relationships that have been drastically altered.

“…I think it’s the family members who are going to have to make the biggest adjustment. I think that although their whole life is upside down they’re the ones this has affected the most they’re just doing the best they can to survive…” (partner).

Many partners expressed experiencing a process where changes in their relationships were sometimes volatile and difficult to manage or accept early on but then achieving a point where things leveled off. There was a sense that if one were able to withstand the first couple to three years of instability then life would again achieve a sort of normalcy but that the relationship would be at a significantly different quality than pre TBI. Some of the respondents stressed how important it was to remain strong, emotionally, in order to withstand such significant and acute transformations to their loved ones and relationships.

A shift from initial to follow-up interviews was perceived in the ways in which partners demonstrated increased skills and confidence in dealing with challenges and facilitating the most optimal behaviors in survivors.
“…Now I try to say, ‘Hey, I paid this. This came in’, and a lot of times he doesn’t remember from week to week. But, I still want to make him feel a part of without making him worry…and I’ll say to the kids…. ‘See what your Dad has to say’ instead of it being me all the time and that’s something I had to learn too…he already feels bad. How can we make him feel a part of….You still have to make them feel important. They’ve been through so much already” (partner).

There was a sense that if both partners possessed a desire to stay together and work on their relationship after TBI it was critical that they both accept the changes that resulted from the injury. Some partners stressed the fact that if they weren’t able to accept inevitable changes in their loved ones and the relationship than it might be best to consider separating from each other to avoid potential problems in the future.

“…if they really want to be together is do what M. and I have done which is talk it out and find out what it is and the things that you can’t change you just have to either accept it or move on and that’s it in a nutshell…There’s nothing that could keep me from being there, going with him because he’s been that type of person in my life” (partner).

Other partners reported that information they received from health professionals in the acute rehabilitation stage regarding challenging behaviors of their loved one was not necessarily valid as time progressed. Respondents said they were able to detect changes that were, at times, affirming to their relationships. The dynamic nature of TBI was more evident to participants at follow-up as their partners continued to adjust and recover.

“…I was told things would never be the same. They said he’d be more like a robot fulfilling his own needs and it was for a while but he’s changing” (partner).

Whether partners experienced changes to be for the better or not sometimes was considered to depend mostly upon one’s attitude and perspective about the changes that occur as a result of one partner sustaining a TBI versus the actual changes. In the follow up interviews, there was more of a conviction from the majority of partners that their loved ones would never be who they were prior to their injury, but, the important factor was whether couples could move on from that point and re-create a “new” life or relationship with each other.
“...it doesn’t get better. They’re never going to be who they were. It may get better as time goes on and I think that’s because it’s a learning experience. It gets better because you know how to deal with things...” (partner).

In essence, survivors tended to report concrete positive changes in their relationships, such as improved communication, physical, behavioral or cognitive skills. For partners, however, improvements were conceptualized more as a process of learning to accept changes in their significant others, themselves, and, ultimately, their intimate relationships. Many partners expressed efforts to go beyond the challenges and navigate a “new” journey that mandated adjusting one’s expectations and embracing a new life for themselves and their loved ones.

3. Healthcare Professionals

Ongoing problems within healthcare from the perspectives of both survivors and partners included the lack of follow-up care, education, counseling, advocacy, case management, social supports and practical help. Although in general, couples seemed to be doing better since initial interviews in terms of communication and acceptance of changes it did not seem that this was the result of improved or increased healthcare involvement. In fact, it appeared that couples were faring better in spite of the significant gaps in services. The question remains as to how much better they might be doing if they also were buffered with a comprehensive continuum of TBI supports and resources. Survivor and partner responses are described together since their views on this topic were generally similar.

a. Ongoing problems in healthcare for TBI

i. Lack of long-term support or services

Both groups stressed that there was a significant gap in services and support from acute rehabilitation to being in the community or at home. Often, participants spoke about services abruptly ending with no follow-up care whatsoever. This contributed to some survivors not
having the support they and their partners needed when problems emerged that were not necessarily evident during their rehabilitation phase.

“…and rehab did say that they dropped the ball and I didn’t notice a lot of deficits because I was working so hard on my physical until a year or so down the line and I said to rehab. ‘No, I’m fine, I’m fine’, not realizing, but, they should have spoken to whoever was closest to me, my spouse or my partner…” (survivor).

Most partners expressed feeling lost and unsupported after their loved ones left rehabilitation. They often feared not having the resources available if and when problems arose that they felt unprepared to manage. For example, many partners agreed that their loved ones displayed behavioral problems after coming home such as anger, agitation, confusion and even paranoia. Partners felt vulnerable trying to figure things out on their own and felt there was a huge void regarding receiving information or being educated regarding challenges or change they might be confronted with within their intimate relationships.

“…our medical community is lacking in the post-traumatic brain injured patient and family of any type of follow-up. These two calls have been the only time M. and I have heard from anybody regarding how is he doing, let me do a follow up…Why don’t they have a social worker give us a call once a year? ‘How are you doing’? ‘Is there anything I can offer you’? …..He left and that was it. Done deal. Now who am I going to call if I have trouble with intimacy or if I have trouble with medications?…If I wasn’t a nurse I might not know what to ask for…those are the key elements that are missing here…I’ve come from two or three different, top facilities that are trained to work with people with brain injuries and if I come away saying I surely don’t think that they’ve given the family what they need, what about some of these other facilities that don’t have half of what they gave us?” (partner).

Many partners expressed that they received adequate information and training regarding basic daily activities but there was a profound disconnect regarding training for integrating back into the family and community.

“…When you get out of rehab and you can dress yourself and function with normal basic things, there’s no help after that” (partner).
ii. **Lack of support groups/outlets for social network support**

Although several participants agreed that TBI support groups were or would have been beneficial regarding increasing understanding about TBI and relationships and forming social connections to stave against social isolation or getting ingratiated into a disability community.

“...I know we have to get on with our lives, but, our lives are forever changed. We are in a disabled world now. I think it would have been wonderful for S.-I looked for support groups for her and there were none” (partner).

Partners reiterated that their loved one’s TBI often resulted in loss of friends for each partner which did not improve, necessarily, with time. Therefore, partners often lamented that they wished for more social connections, even indirectly, through friendships on that might develop by participating in TBI support groups. Many partners felt that they either were not being made aware of such groups or they didn’t exist, but, wished they did.

“...and more connection after you’re done with everything...I’m sure I’m not the only one who lost friends but we just didn’t feel like we got help from our church, from anyone else…I feel like I’m just floating out there with C. and our problems and I would like to belong, even if it’s disability, I don’t have a problem belonging to that disability. ..I feel like we’re all alone. I feel like we’re all scattered about and we need to be brought together…nobody does anything for brain injury. Does anybody care besides you guys”? (partner)

iii. **Lack of education and training regarding counseling**

If participants were involved in individual or couples counseling, they reported that it was because they took the initiative to seek this support on their own and not because it was arranged through healthcare professionals when they were in rehabilitation.

“...that should have been done right after she was released and if it wasn’t for us pushing it she’d still be sitting and getting frustrated everyday saying why can’t I remember things” (partner).

Some partners who healthcare education and training had admitted to not having enough formal training in counseling, to the detriment of their TBI patients and partners.
“…any of the supportive counseling piece is definitely missing as a whole and we don’t have a lot of training in it…I don’t think it’s a huge chunk of our education” (partner).

iv. Insensitive or misinformed professionals/disregard or respect for partner input

Since initial interviews, partners often gained more insight into the needs and limitations of their loved ones. As a result, they became more knowledgeable about how to best support and advocate for their mates, specifically, in the context of interactions with healthcare professionals. Ironically, it seemed that the more adept partners became at best representing their loved ones, the more professionals seemed to discount their involvement, perceiving it as interfering.

“I tell them he can’t sign certain papers. They let him sign them. I told them that I need to come in with him when he is seeing the doctor. They tell me that I have to wait outside that he has to do this himself. I tell him beforehand and tell him, ‘You can’t because he’ll give the nurse the wrong information about what he’s taking’. Well, they’re like, ‘It’s his decision’. I’m like, ‘No, you don’t understand, I’m his legal guardian’. I give them a letter and they just don’t get it…The doctor totally disrespected me. He refused to talk to me…It’s the health professionals and the way they look at the spouse…like you robbed the bank…” (partner)

4. Recommendations

Recommendations for improved intimacy services and resources for TBI survivors and partners were reiterated as long-term support and follow-up that incorporates ongoing education and training for professionals and families, advocacy services, support groups, practical assistance and acknowledging uninjured partner as critical part of team. It was also recommended that professionals be better educated and trained in specific aspects of brain injury, particularly, its impact on intimate relationships. Participants expressed a need for case managers or professional advocates, practical support, TBI education and training, counseling, support groups.

a. Case management/advocacy

The most commonly cited need by both survivors and partners was long-term case management for couples or families. They felt that someone who was an expert in TBI who was
aware of the various services and supports that couples might benefit from along the process of recovery was vitally needed.

“...I think probably a caseworker could be really very important for a lot of people...they don’t know who to talk to or maybe they need help with job skills training or something like that...unless they’re involved with the Vocational Rehab, they’re not gonna get that…” (survivor).

Some respondents felt that a case manager should act as a liaison and field specific problems or issues to the appropriate professional or resource.

“...if there was somebody other than the doctor...’I’m so and so and I’m here to help you with any type of question you might have about anything. I can help you get you to the person that you would need”...like a liaison...like a personal case manager” (survivor).

Many survivors were cognizant that since changes personally, and in one’s relationships occurred as an ongoing process for many years there was a need to be in contact with professionals to regularly “check in” and monitor how they were doing.

“I think beyond is so important. Because you’re so overwhelmed at the time... So, I really think you should be followed up 1 year, 2 years, 3 years down the line-it doesn’t exist ...it should be mandatory to talk to patients and family members. Follow up…” (survivor)

There was a suggestion that alternate methods of communication regarding educating about TBI services, resources or supports would be useful, as well, as in the form of a community network bulletin or a disability resource drop-in center.

“There’s no central place-absolutely. Just a place where you can find all resources...Even if it’s a telephone, talking to someone on the phone or a community bulletin board…” (survivor).

Some survivors told of how they would have benefitted by learning about community resources rather than having to struggle initially and found out about a transportation service serendipitously.

“...Like it took me forever to find this Pace bus that I take out here. It was one of the drivers who told me, ‘Do you have this special card they give to handicapped people and you get the rides free?’ … I was like, I could have done it months ago. Just let people aware of the fact the things they can benefit from especially getting older…” (survivor).
b. **Practical day to day services**

One survivor reported that her initial recommendation for practical support, such as services helping couples with day to day chores like cleaning, shopping or cooking still held when asked at follow up interview. She felt that practical services would allow couples to have more time with each other and not be so fatigued and stressed, thereby, contributing to well-being.

“…I almost think they’re more important than psychological help. They need actual help, not just to talk about things” (survivor).

c. **TBI education/training**

Some participants felt, that since initial interview, they realized that there was a need for education regarding coming to terms with being with a different person since TBI. They felt that although this was an experience generally experienced by all couples, it was rarely if ever addressed formally.

“This has never been addressed in rehab but I think it should be…she’s still dealing with the person, the attitudes and morals and things that I had before and I’ve changed from that person so that’s a really tricky thing. That’s not addressed at…it’s never been talked about” (survivor).

It was stressed that education was necessary to help partners understand what their loved ones were experiencing.

“Oh, man…You have to understand what they’re going through in order to cope and deal with it and help them” (partner)

The importance of including both partners was considered critical to the well-being of the relationship. Education, training, counseling and any other services were felt to be best directed to both survivor and partner, for the long-term outcome to be favorable.

“…keep the communication lines open because it’s been my life experience that if the communication piece isn’t there than the intimacy piece, for sure, is not going to be healthy. And just being open to the fact that you’re not only treating the patient, but, you’re also treating the family and significant other…that piece is for sure something that would be helpful for health professionals to know” (partner).
When professionals went out of their way to include both partners and to recognize the partner it was noted as very positive and important in conceiving of the professional patient/family relationship as very worthwhile and meaningful.

“…They really do take time with us. When he goes sees his psychiatrist…I sat in with him so it’s awesome and each of his doctors always say, ‘And, how are you doing, D.’? Yeah, thank you for noticing…that’s huge. It makes you feel good” (partner).

Counseling, like education, was felt to be something that needed to be more formalized and consistent, both individually and for couples. This was expressed in the following responses:

“Marriage counseling…It helped. We communicated with our counselor individually and then communicated together” (survivor).

“…why there’s such a need for specialized psychologists is that it can bring a lot of turmoil into a relationship. A lot of emotion. You need somebody who can be in control who can be a third part…I truly love my husband and I want some type of functioning relationship…” (survivor).

“…and that was one of the stipulations that she get help because we weren’t going anywhere and we wouldn’t be together. I didn’t know what was her brain and what was emotional. Can she really not remember, is she not listening to me?” (partner)

d. Support groups

As in initial interviews, most participants felt that having TBI support groups were very important. This forum was felt to be particularly beneficial to just feel a part of a group of like-minded people even if one didn’t feel as if they wanted to actively participate in the discussion. Groups for the family were recommended in order to discuss similar issues and gain support from each other.

“…more support groups for family members….it makes you feel better inside…it makes you feel better inside…if other people have the same issues that takes the edge off…It lessens the load…Even if you just go to that group and you don’t say a word and you just listen” (partner)
Social groups were also recommended in the hopes of getting connected and building social relationships.

“...I’m sure there’s hundreds of people and families who are going through what we’re going through. I would be nice if we could go on a picnic because we could let our guard down and say, ‘Yeah, whatever, he said something bad’...Somewhere that we can relate to and say, ‘Hey, do you want to go for coffee’? It’s ok if they have a tantrum’...but, more connection…” (partner)

e. **Peer mentor support group**

Some participants felt that their experiences would be useful to share with other people just newly injured, as in a peer mentor capacity. It seemed that since initial interviews, there was a greater emphasis of feeling prepared and wanting to help other people, perhaps, gaining experience with time.

“...perhaps there is some type of a system where new people might have a support group for people like M. or myself. ...I haven’t found a support group for this type of thing...if I were to sit down with someone who had a husband and said to them ‘Let me tell you some of my experiences, what you need to anticipate...you’d need training. You got to say the right stuff...there are lots of us out there that would be certainly willing to extend to others and it’s just not being utilized at all. If there was I’d join it, I got to tell you” (partner).

Support through participation in a local or national brain injury association was mentioned by one participant as helping him to gain a sense of belonging to a group and as a way to learn more about brain injury. He stated that he started becoming more active in the association since initial interview and anticipated that he would continue his involvement because it made him feel a part of a community. He recommended this to other people as well.

“...I’m on the board of directors for the brain injury association...We have our meetings every third Saturday of the month. And we have a conference also in October. You could learn a lot about brain injury there” (survivor).

f. **Participation in qualitative research**

Since initial interview, additional participants commented that their participation in the study was positive in terms of having an opportunity to express themselves and describe their
experiences. Some participants felt that the questions asked easy to understand and accessible, and, thus, a positive experience.

“It’s nice that you guys are very understanding…The questions aren’t crazy. They’re very simple and very basic questions…And, so it’s nice the way that we have the conversation that you and I are having… it’s a very basic question ‘cause then you can figure out serious results because the questions don’t get really crazy or really advanced…” (survivor)

Some people felt that the opportunity to be honest with their feelings was liberating because they felt as if they would hurt their partner’s feelings or create anxiety if they confided in them about their concerns.

“…. It’s good to talk to other people objectively…because there may be things that I want to talk about but I can’t talk about then with M. I might have that worry about that one certain bill and I don’t want to go to him with that and make him worry. So, it’s good to just talk. It really is” (partner)

Feeling as if they were being listened to and their perspectives were important was mentioned as being a very positive experience, especially because many participants shared all along that they hadn’t had the opportunity previously to tell their stories.

“…you guys have been wonderful to me too because, even though you’re doing this just the fact that you’re listening to what we’re saying. I’m really, really thankful that you’re even taking time to put something together” (partner).

Sharing one’s viewpoints was also helpful to some people because it allowed them to gain a deeper perspective on how their experiences impacted them and their relationships. In many instances, this was the first time participants were given an opportunity to share their perspectives.

“…I’m glad that we were able to even have this time. I think that what it’s done for us is made us also sit back and think and realize what’s happening” (partner).
C. **Focus Groups**

Four survivors and three partners participated in the focus groups that followed follow-up interviews. The focus groups enabled the reinforcement and elaboration of the major and sub themes that were identified from initial interviews. During the focus groups participants had the opportunity to meet with and share their experiences with each other.

1. **Survivor Focus Group**

Survivors talked about being grateful to their partners for their unconditional love and support and they were grateful to be alive.

“I don’t that my partner knew how much I appreciated her and I don’t know if other people appreciated her as much as she should have been…but, if you want to get better you can’t concentrate on anything but yourself” (survivor).

Some survivors reiterated that they struggled with feeling resentful for the surveillance by their partners but also understood that their partners supervised them because of attention and memory difficulties as a result of their TBI.

“I’m walking a tight wire. That’s one of my biggest complaints. But, I understand because there are times that I will forget to turn the stove off. There are days that I’m much more cognitive and aware, if I’m stressed and not rested my memory’s gone…She gets frustrated and I get frustrated…” (survivor).

Loss of roles such as friend and worker affected the participants in negative ways, although one survivor felt that her friends stuck by her and her partner for the most part.

Survivors discussed the fact that they were in the process of continuing to accept their changes and adjusting to performing activities with modifications, as necessary.

“…I can’t do the things I used to do. My memory is impaired and it was really difficult…So, I hate that I have changed but, I have…” (survivor).
All the survivors acknowledged feeling changes within their intimate relationships in terms of their stamina and cognitive skills. They felt that their cognitive changes were the cause for stress and fatigue for their partners who had to take on additional responsibilities.

“I think it puts more stress on a relationship if I can’t get on a ladder to change a light bulb. It’s one more thing she has to do” (survivor).

As far as healthcare professionals and services, all agreed that there were not enough TBI services and uninjured partners were not involved enough in the entire rehabilitation process. They all reiterated that they had no services or supports related to intimacy or relationships.

When asked what services were most unhelpful, it was unanimous that not having supports to help with intimacy was the most negative aspect of the existing healthcare for TBI. One survivor expressed that he wished his healthcare providers took the initiative to find out if he was doing ok because he was actually experiencing a lot of fatigue and decreased frustration tolerance after he was home but he wasn’t provided with resources to address these issues. He felt that these problems negatively affected his communication with his spouse.

“…once I got to outpatient rehab I had no energy. That took a long time to get back…My daughter was 8 years old and the noise level drove me nuts. I never had that before. I couldn’t fight it. I went back to outpatient rehab and told her what was going on. She told me ‘We were wondering when you were going to come back’. Why didn’t she tell me before?” (survivor).

The most helpful aspects of healthcare were professionals who were compassionate, knowledgeable and who reassured couples that things would take time. They all recommended support and education about TBI for couples. All the participants also thought that mentorship by veteran couples would be very beneficial because they would be able to relate their experiences.

“A volunteer helped me tremendously who had recovered from brain injury and came in and talked to me. To see someone who personally recovered as much as she did and talked about practical issues” (survivor).

“…would have given a heads up of what’s coming your way-can relate to you. There could be more of this. It’s a good idea” (survivor).
Other recommendations that survivors agreed upon included increased education and training focusing on going home and addressing role change for both partners. Included in this was a call for follow-up after returning home.

“They should add check in with you and your partner. I wasn’t always aware of what I could and couldn’t do. You don’t always get a true answer from brain injured patients….We wouldn’t have known that as you get better and better, more things come up” (survivor).

All agreed also that emphasis needed to be on long term as well as acute short term issues and having transition training to re-integrate into one’s community.

“Why don’t they give you information or tell you, ‘You may experience this, you may experience that’ Instead of saying, ‘I didn’t want to tell you’. I’m more afraid of not knowing” (survivor).

The survivors also discussed having a safety net such as being provided with phone numbers to call each other or other contact information to check in and make sure everyone was adjusting well, if one agreed to participate in such a program. All the survivors agreed that it would be very helpful to have some sort of community drop-in TBI resource center to share information and experiences with other survivors and to also have professionals available, as needed. A written resource guide was recommended, as well, that included listing disability related services and professionals and mentors who had specific experience and interest in TBI.

“They gave me a book of resources, but, it was all resources for wheelchairs, bath tub equipment. It was like, I don’t need that. I have that. I need somebody to talk to. Do you have a phone list? A, list of other brain injured patients contact information. That would be helpful” (survivor).

The participants agreed that support groups were needed particularly for relationship issues.

“…S. would say, ‘I do that?’ things I do that I’m not aware of, she wouldn’t say it unless there was a group…We need three groups, survivors, caregivers and one combined. They need to enact some of these (survivor).
Another survivor also pointed to the fact that separate support groups would be helpful in order to feel comfortable to disclose information that one might not feel comfortable doing in the presence of their partner.

“It’s very important to have separate support groups for partners and survivors. If you get with your husband or wife, you might hold back on saying something, but, just with us, you might be more open to talking about things” (survivor).

2. Partner Focus Group

Partners discussed factors that helped to keep their relationships strong that were having a long-term commitment, feelings of continued love for one’s partner, having things in common and having support from family and professionals.

Challenges to relationships included having little or no family support, loss of friends, loss of emotional connection with one’s spouse and having poor communication. Two of the partners also felt that they were currently struggling with role conflict of being both a “parent” and an intimate partner. One partner shared that these feelings were initially challenging but that she was beginning to feel more positive about her relationship, partly because she made a conscious effort to move ahead and also because her loved one had begun to communicate more with her.

There was a sentiment of adjusting to changes, learning to approach situations differently such as manipulating certain behaviors to get a better outcome.

“…everyday, I said you’re gonna tell me love me. I’m not a quitter. Against all odds…I can cry myself to sleep…because he used to tell me he adored me…So, I kept saying, ‘I love you C.’. Persistence, I thought. I’ve got to be your advocate. We persisted and pushed to have to find a way to manipulate the situation to get out of it what you want” (partner).

Partners felt that it was helpful to talk to each other about their similar experiences.

“Just talking to you is very inspiring” (partner).
One partner expressed her anger at the fact that her spouse had a TBI and was changed person. She admitted to having a difficult time adjusting and accepting her different circumstances.

“…I’m angry, I’m super angry….I’m trying to work through it and not be angry anymore but I miss my husband…I want my relationship back. I envy you guys and then you don’t even have friends anymore. It really affects your life” (partner).

One partner responded and attempted to assuage the tension the other partner was experiencing. It was interesting to observe the support that these partners were able to offer one another. The dynamic process of adjustment was evident in this statement as well.

“…you’ll get to a point that you will get over it. Think it was in the 4th, 5th year that I felt angry but I couldn’t show it…I thought, I have to move on…I’m not angry anymore…I’m in his life and I’m gonna help him have a good life. I want him to be happy now” (partner).

Health care recommendations included TBI education for professionals and couples, practical day to day support services to ease responsibilities.

“…There is so much responsibility heaped onto caregivers…We don’t have it in the system now but an important practical daily support would be day to day practical support so you can ease off and have more time for relationships…” (partner).

All partners also agreed they had no preparation for bringing their significant others home and this was very difficult because they all felt they were married to a different person. There was agreement that training needed to focus on how to be a partnership again.

“…have to learn how to evolve again as a family unit. It’s the interaction between the two, meshing together” (partner).

“…and, learn how to re-do; to start again together” (partner).

All partners also strongly agreed that all professionals need further TBI training.

“the doctors don’t have TBI training and it’s a big problem…They gave me a diabetes doctor and he doesn’t understand TBI. He saw C. taking out a screwdriver and then remembered, ‘Oh, yeah’. Then he understood he needs an advocate” (partner).
It was felt that there needs to be a neutral advocate because existing healthcare professionals often have conflicting interests, that of the patient and their family and also for the institution that they are connected with.

One important aspect of the focus groups was that participants offered support to each other and reported that these types of groups were greatly beneficial in order to validate their experiences. This is captured in this response from one uninjured participant who listened to another uninjured woman that her relationship with her spouse improved with time: “That gives me hope” (partner).

Overall, the focus groups contributed to an elaboration of the themes which, in turn, helped to expand the researchers’ interpretation and analysis of the preliminary data.

In summary, the responses from initial and follow-up interviews and focus groups reflected the multiple and significant ways that TBI affects intimacy for the couples in this study. Interestingly, several of the core themes that emerged initially, such as commitment to the relationship, were evident as well at follow-up. However, there were also unique themes represented at follow up that were instructive for the dynamic nature of TBI.

Throughout this chapter, there was an attempt, when appropriate, to describe responses of survivors and partners separately in order to appreciate the participants as a working unit who also possessed their own individual responses and perspectives. This duality signifies the challenge of performing couples counseling with TBI couples. Because survivors and partners often expressed their unique viewpoints on the issues addressed in this research, clinically, it would seem critical to help each partner understand and appreciate each other’s’ perspectives so that they might be better guided to work together to foster collaborative relationships. These ideas will be explored in more depth in the next chapter.
VI. DISCUSSION

Unique aspects of the current study included the participation of both TBI survivors and their uninjured partners, the use of multiple methods (individual interviews and focus groups), the use of initial and follow-up interviews, attention to the social dynamics as well as medical aspects of the TBI experience, and an emphasis on capturing positive as well as challenging aspects of intimacy following TBI. Much of the existing TBI and relationship literature has emphasized negative factors such as caregiver burden or marital disintegration after TBI (Norup et al., 2010; Godwin et al., 2011), captured couples’ experiences at only one point in time (Hammond et al., 2011), or exclusively examined married couples who were together before the TBI (Kreutzer et al., 2009). The need to gain perspectives from both survivors and uninjured partners is supported in the recent literature as an optimal method of yielding a richer and more complete understanding of intimacy after TBI (Godwin et al., 2011; Vangel et al., 2011).

An effort was made in this research to sample the perspectives of various people who have previously been underrepresented in the literature, including male uninjured partners, female TBI survivors, unmarried couples, individuals from various racial, cultural and ethnic backgrounds, and couples with relationships established after TBI. To balance the literature’s focus on the individual’s physiological and psychological losses, interview questions about social factors that might mediate the impact of TBI on intimate relationships were included.

Participants’ experiences with intimacy after TBI were complex, and a commitment to preserve this complexity in reporting the research findings is important in order to represent their experiences most accurately and comprehensively. In one sense, the findings of this study are consistent with previous literature that illuminates factors such as survivor guilt for having
sustained a TBI and feelings of stress, fatigue, role conflict and caregiver “burden” on the part of uninjured partners (Norup et al., 2010; Perlesz et al., 1999).

In another sense, this research served to extend and inform the existing TBI and relationship knowledge base by highlighting the positive as well as difficult aspects of intimacy after TBI. Findings that support the existing literature and findings that offer new insights are discussed in the following sections.

A. **Change**

Change was the greatest challenge reported in this research. Participants went to great lengths to achieve balance, acknowledging and accepting profound and often permanent changes within themselves and their relationships. These experiences were framed as an ongoing and dynamic process that took time and patience, even for couples whose relationships were established after TBI. Changes are a challenge in any relationship in which trauma or illness occurs but the unique feature of TBI, according to the participants, was its widespread impact not just physically but emotionally, behaviorally and cognitively, rendering both survivors and partners vastly changed, often in permanent ways.

There were “give and take” advantages and disadvantages of being together before versus after TBI. Couples who were together before TBI talked of having a strong base of friendship or a commitment that helped to bolster them against the challenges brought about after TBI. In another sense, they also expressed grief and loss for the partnership they had had before injury and living with a “new person,” leaving them keenly aware of the changes and losses. Couples established after injury did not go through the experience of losing the person they were originally drawn to. They met their survivor post-injury and chose to be together in the context of whatever issues were associated with the TBI. These couples were more aware of the realities
of TBI-related impairments and complications from the outset. However, they lacked the strong background and history of a committed relationship to help them shoulder the challenges of TBI.

A compelling dynamic regarding change was evident throughout this research. On the one hand, survivors frequently described difficulties navigating day to day with the loss of their former roles or sense of selves. They lamented not being able to relate to their significant others in the same ways and felt their partners responded differently to them as compared to pre-injury. Similarly, partners expressed many struggles related to feeling alienated from loved ones who seemed vastly changed since injury. In this sense, participants’ responses supported previous research that suggested caregiving spouses develop diminished marital vulnerability and withdraw emotionally after their partner’s TBI because of the imbalance of caregiver and intimate partner roles (Gosling and Oddy, 1999; Hammond et al., 2011; Kravetz et al., 1995). On the other hand, this study suggests that change can be embraced when associated with transformation of grief or loss to acceptance and reconstruction. Because participants were able to share their personal experiences at two different time points, there was an opportunity to appreciate how their perspectives transform over time. For instance, many participants’ perspectives at follow-up interviews were characterized by a settling in to changes, appreciation of survivors’ hard work to improve their skills and further acceptance of reconstructed selves or relationships. These ideas diverge somewhat from the literature that suggests that survivors and significant others express more static feelings of negativity, hopelessness and comparisons of past with present after TBI (Hammond et al., 2011). However, it is interesting that Hammond et al. (2011) found ambivalence in spouse’s reactions to their mates in themes such as “pulling apart and pulling together.” These nuanced emotions expressed by participants may have
reflected the researchers’ utilization of in-depth open-ended interviews that helped to tease out the complexities of the spouses’ experiences.

The current study extended these ideas by asking for the experiences of both survivor and partner at different points in time. The findings moved beyond the existing literature in that couples expressed more cohesion, less resentment and more hopefulness that their intimate relationships were improving, even if much changed from prior to post TBI.

An effort was made throughout this research to build a rapport with participants to make them feel comfortable in sharing their perspectives. Open-ended interview questions encouraged participants to express the complexity of their situations more fully than might have been possible with other types of methods. In addition, follow-up interviews provided an opportunity for participants to expand on their responses in further detail and to reflect upon the passage of time as affecting their intimacy experiences.

B. Communication

Communication challenges were a prominent theme throughout this research. Interestingly, communication issues were perceived differently and with more ambivalence for partners than survivors. The latter felt, overall, that many relationship problems could be resolved through discussion with their significant others but they did not always recognize that their communication styles were different than prior to TBI. In contrast, uninjured partners described making a conscious effort to facilitate more productive and meaningful exchanges with their mates since TBI, as opposed to feeling that there was actual improved communication. One of the difficulties experienced by partners was the comparison they made between pre and post TBI interactions with their mates, often citing a lack of passion or more superficial types of communication since their loved one’s TBI. Because survivors did not share the same memories
as their partners, they were spared to some extent the pain of comparisons. Communication issues are not unique to couples with TBI but having one partner with TBI adds another layer of difficulty to relationships. Perceptions about each other tend not to get discussed and, therefore, contribute to relationship stress and conflict.

Good communication has been identified as a key factor contributing to healthy interpersonal relationships in the intimacy theoretical literature (Gaudet et al., 2001; Hook et al., 2003; Lippert & Prager, 2001; Mackey et al., 2000; Mills and Turnbull, 2004). This study tended to support this idea. Women participants tended to measure the quality of their verbal exchanges as a barometer of relationship strength whereas more of the men participants shared that being physically close to and doing things with their partners was important to feeling intimate with their mates. This supports the work described by Mackey et al. (2000) and Lippert and Prager (2001) regarding psychological intimacy between couples. Gender preferences tend to be characterized by men preferring proximity and interdependence and women tending towards sharing verbal exchanges (Mackey et al., 2000). This was illustrated by one woman partner who shared during the focus group that her repeated efforts to talk to her loved one in spite of his cognitive and behavioral challenges was the factor that helped her to strengthen her commitment to the relationship. There were also some exceptions to the psychological intimacy theory of Mackey et al. (2000). For instance, one of the men partners shared that his most striking experience of loss since his wife’s TBI was his inability to talk to her on the same intellectual and emotional level that he was able to pre-TBI. This example illustrates that men do not always identify proximity as more important than verbal communication in their intimate relationships.
Interestingly, many of the couples reported more overall relationship stability from initial to follow up interviews than expected. Explanations for increased stability usually centered on couples feeling as though their communication was improving, either through increased day to day exchanges or through partners readjusting their expectations. When volunteering for this study, the participants might have been better communicators than other couples, and they underscored how important communication was in consistently putting in the effort to work at their relationships. Thus, the variable of communication may have been skewed in the sample of this study but it does lend confirmation that positive emotional sharing between partners is a vital component of strong partnerships.

It is also interesting to ponder whether those couples who are better able to cope with TBI have built up reserves or resources of responsiveness to previous positive events. The fact is that the couples in this study who tended to express that they were “weathering the storm together” and were committed to each other “through thick and thin” also affirmed a high degree of pre-injury relationship commitment, closeness and a tendency to support each other’s successes such as career and educational pursuits. This would support the theoretical frameworks described by Hook et al. (2003) who reported that both men and women respond favorably to giving and receiving emotional support in intimate relationships. Gable et al. (2006) also demonstrated that partner response to positive event disclosure was correlated to long-term relationship well-being. Women responded favorably to support of negative and positive event disclosure but only in the short-term (Gable et al., 2006). If, in fact, partners in this study learned how to communicate the preferred types of support to each other, through their perseverance and commitment to stay together, this might help to explain decreased relationship fragility over time.
C. **Sexual Expression**

Sexual expression of intimacy was a key factor in feeling loving towards each other for most of the participants. Several survivors lamented their lack of abilities or attractiveness and were worried that their loved ones would be unfulfilled. This reflects previous TBI and relationship research that illustrates how men survivors have decreased self-esteem regarding how they function sexually since TBI (Jones & Curtain, 2011; Shrout et al., 2006). Men survivors are thought to have added pressure to live up to societal images of the “virile” and “strong” man (Jones & Curtain, 2011). However, one of woman survivors in this study lamented that she could not express herself intimately like she did prior to injury. Perhaps the small number of women survivors was a limitation to further identifying sexual expression difficulties unique to women. Emerging notions of transformation from negative to positive self-acceptance of male TBI survivors warrants more studies examining both genders in terms of their sense of sexual identities after TBI (Jones & Curtain, 2011).

Many survivors reported that the sexual and physical changes resulting from their TBI made them feel less “attractive,” “sexy” or “playful.” They lamented that their current sense of self as an intimate partner did not meet the standards or their image of what they believed a legitimate intimate or sexual partner should be. One survivor, for example, described not being able to give her partner a “real” kiss or hug because the right side of her body was not functioning like it was before her injury. Other survivors also described feeling sexually “deficient” or not “normal” as a result of their physical or cognitive impairments. Even some uninjured partners envisioned themselves as inadequate because of the challenges of financially or emotionally meeting the needs of their mates. In essence, participants tended to attribute their own or their mates’ physical, cognitive or emotional limitations as barriers to intimacy rather than appreciating how
social norms of what masculinity or femininity are may have been more disabbling than any impairment they were confronting. Situating these issues within a social model of disability that considers societal misconceptions and stereotypes of sexuality and disability would be important in dispersing negative images and helpful to guide participants in reinterpreting how they view intimacy after TBI.

Some of the partners did express a sense of loss because their mates’ “robotic” gestures marked a significant departure from their intimacy prior to TBI. The partners expressed trepidation about addressing this with the survivors; they believed that their loved ones did not necessarily recall the details of how they performed previously and, therefore, wanted to spare their loved ones’ feelings. Accordingly, uninjured partners often experienced a dilemma regarding feeling somewhat unfulfilled sexually and emotionally because of the loss of pre-TBI intimacy but at the same time having a desire to shield their partners from feeling upset about their impairments or differences.

Feelings of inadequacy or frustration regarding sexual expression did not seem to have the same significance for the same-sexed couple in this study as compared to heterosexual couples. Instead, this couple expressed feeling emotionally alienated from each other. The uninjured partner, in particular, revealed that she and her loved one lacked meaningful disclosure and that their relationship was precarious as a result. Past intimacy research focusing on heterosexual and same sex couples cited lesbian couples ranking self-disclosure and psychological intimacy as most critical to relationship satisfaction (Mackey et al., 2000).

The presence of TBI may compound the challenges of achieving psychological or emotional closeness in partnerships already outside of the mainstream, and lesbian couples may be at particular risk for relationship deterioration. As discussed when examining general
communication styles of couples, Lippert and Prager (2001) and Mackey (2000) claim that women more often associate intimacy with self-disclosure than men. Perhaps this finding illuminates this couple’s added challenges regarding not meeting each other’s needs for emotional closeness. Further investigation of same sex couples would help to increase understanding of specific issues confronting these individuals.

D. Relevant Theoretical Frameworks

Data from this study supported family systems (Gan et al., 2006; Laori, 2003; Vangel et al., 2011) and trauma (Goff et al., 2006; Mills & Turnbull, 2004) theoretical frameworks. Family systems and trauma theory rationales consider that both partners form a balanced pattern of relationships but that injury such as TBI can disrupt the flow and structure of the family. Goff et al. (2006) underscore the relevance of appreciating these dynamics in this statement: “Understanding how trauma effects manifest within the couple and family system will improve clinicians’ ability to intervene successfully with these client systems” (p. 459). These theories have not previously been applied to the study of intimacy after TBI. However, in this study, TBI was conceptualized as reciprocally affecting both partners in the relationship. Namely, trauma to one partner affected the other partner as well and then each partner continued to be affected by the other. Many of the partners talked about being a “different person” since their loved ones’ injury. They described experiencing a “metamorphosis” as a result of living through the TBI experience with their loved one. Trauma, in general, affects intimate relationships in complex ways (Goff et al., 2006; Mills & Turnbull, 2004) including threatening the stability and communication between partners. These ideas are instructive when thinking about how intimacy affects couples in which one partner sustained a TBI because permanent and profound changes that occur as a result of TBI make these couples even more vulnerable to relationship challenges.
It was evident that partners did much more than react to their loved one’s injuries; each partner in the dyad inextricably affected the others’ well-being. This finding expands the TBI and intimacy knowledge base in several ways. It clearly portrays the uninjured partner as having a more significant role in relationship stability and quality after TBI than has been previously appreciated in much of the TBI and relationship research (Godwin et al., 2011). In addition, it suggests that when survivors react to their significant others in ways that contradict the stereotypes of blunted or dysfunctional affect after TBI, they effect positive changes not only in their partners but in their overall relationships. Last, the metamorphosis that many of the partners reported experiencing as a result of their mates’ TBI gives credibility to the concept that TBI shapes the lives of couples, not just individuals. Several of the uninjured partners related that their metamorphosis included a conscious effort to reconstruct or recreate their relationships from their initial experiences of loss of what once was or, in the case of partners who met after TBI, what they would imagine their relationships could be if TBI were not a factor. Participants’ creations of “new” realities reflects the models described by Crisp (1993), Nochi (1998) and Mills and Turnbull (2004) that conceptualize TBI adjustment as a transformation of reality to more relevant and acceptable ones that embrace rather than reject change. Transformed selves and experiences of loss through others’ assumptions are constructs that would be interesting and important to explore in terms of how they affect the intimate relations of couples after TBI. Traditional TBI intervention studies have emphasized amelioration of impairments versus incorporation of and accommodation of differences (Aloni et al., 1999). Since the TBI relationship literature has not explored these concepts in relation to intimacy, the experiences described in this study extend the knowledge base and offer potential for relationship
interventions that inform new ways of interpreting and embodying disability and intimacy (Anderson and Kitchin, 2000; Gaudet et al., 2001).

E. **Support and Coping**

The correlation between partner support and survivor well-being is well established in the literature (Levack et al., 2010) but uninjured partners in this study affirmed that a significant factor for them to feel emotionally invested and committed to their partner and their relationship was for them to feel loved and supported by their injured loved ones. Feeling appreciated by survivors also contributed to partners feeling motivated to struggle through challenging and uncertain times. This finding contrasts with Oddy and Gosling’s (1999) conclusion that uninjured partners are not as vulnerable or insecure about the possibility of their partners leaving or becoming disenchanted with them. Notably, the majority of partners in this study reinforced the idea that their self-concepts and hopefulness about the future were significantly affected by how their survivor partners responded to them emotionally. In fact, during both initial and follow-up interviews, many of the partners made a point to express how important they felt it was to feel loved and appreciated by their injured mates. These concepts challenge current TBI literature that theorizes that although survivors are dependent upon their partners for their self-concept, partners’ self-concept is not affected by their survivor mates (Blais & Boisvert, 2007). Although positive coping for survivors and partners has been related to active problem-solving, higher educational attainment, and seeking of social support outside relationships (Wolters, Stapert, Brands, & van Heugten, 2011), the importance of survivors’ demonstration of love, support and appreciation of their mates as a critical factor to relationship well-being has not been well addressed to date.
F. **Gender Differences and Adjustment**

The current research findings challenged other recent research conclusions that propose gender as a critical predictor of caregiver attitudes and adjustment after TBI (Hammond et al., 2011). Hammond et al. (2011) found that women partners expressed longing for or living in the past, wished that their mates would change, and distanced themselves physically and emotionally. Men caregivers, conversely, reportedly expressed more positive experiences in their caregiving roles. It was suggested that women caregivers may have more difficulty accepting their significant others’ injuries. However, the current study revealed little difference in caregiving solely related to gender roles, but, instead suggested the impact of multiple factors on the process of intimacy, such pre-injury relationship status, availability of and quality of social support, and the pre-TBI psychological well-being of partners.

In fact, most of the women partners in this study actually reported many positive experiences with caregiving such as having the opportunity to demonstrate their love and commitment to their injured partners, being grateful that their loved ones survived their injuries and noting that time facilitated the process of reconstructing their lives. Feeney and Collins (2001) also support the notion that partners gain positive benefits from caregiving. Since the majority of the partners in this present study were women, however, it was ultimately difficult to ascertain whether women or men coped better. However, one male partner in this study shared a significant amount of frustration and grief regarding how his wife had changed intellectually and emotionally. He had much difficulty coming to terms with what he described as losses and coped by seeking other women’s companionship. This is an example of how difficult it is to pinpoint whether factors that contribute to relationship stability for one couple will transfer to other couples. As another example, two men partners in this study expressed very different
assessments of their relationship satisfaction in spite of the fact that their spouses had similar cognitive and functional impairments. This contrasts with the study by Kreutzer et al. (2009) indicating that survivor functioning and employment status correlate to partner well-being. The relationships in this study were more nuanced and had more to do with the types of preferred companionship expressed by different partners and their differing thoughts and ideas regarding how they envisioned intimacy. Thus, contrasting with the findings from Hammond (2011), there does not seem to be a simple picture of men’s or women’s reactions to trauma and intimacy. The context is critical and depends more on the relationships couples had and what their needs and expectations are rather than any simple or direct relation to gender.

G. **Relationship Stability**

This research demonstrated that in spite of significant difficulties and hardships, most couples were resilient and wanted to accept their losses and move on to transform their relationships. Most partners believed that their involvement in their mate’s recovery directly affected the well-being of both of them. They contrasted this outcome to their reliance on health care professionals, who, most felt, offered few or no resources and support regarding intimacy, especially for the long term. Some participants reported that the support they had from their families and friends, even if limited, was invaluable to positive adjustment and well-being. Conversely, couples who had difficulty identifying support networks or who talked of diminishing supports expressed more strain and stress within their intimate relationships. Thus, those individuals who fared better seemed to have solid social supports to fall back on for emotional and physical assistance. It also seemed that as time progressed and both partners began to accept the permanency of changes, many partners relied more on their own resources and less on others. The fact that there was a strong inclination towards altering one’s own
thinking and behaviors in an effort to improve the outcome of TBI has significance for counseling and other interventions that could help couples to generate skills and identify relevant resources. It would be interesting in future research to further explore the impact of partners’ conviction that they are capable of positively affecting their relationships through their actions, behaviors and family or friend supports versus relying on external support or assistance.

The majority of partners in this study reported eventually coming to terms with their changed loved ones and their reconstructed relationships but there were a few couples who expressed ongoing difficulty accepting the changes. To examine why some couples may have struggled more than others it was instructive to examine recent work suggesting a relationship between partners’ pre-morbid psychological well-being and perceived satisfaction with social support (Davis et al., 2009; Vangel et al., 2011). There is evidence that partners and survivors are ultimately more susceptible to relationship dysfunction when partners characterize their pre-injury social support as low or absent (Vangel et al., 2011). In the present study, as stated, some partners did admit to having more difficulty coping because they had little or no resources to fall back on when life became more challenging.

H. Social Support

Although social support and TBI was not the primary focus of this study, it did emerge as an integral, if not direct, factor in enabling or impeding intimacy for couples. Many of the couples mentioned that if they had had an affiliation with individual or couples TBI support groups that incorporated TBI education and provided opportunities for bolstering social connections, it might have empowered them to seek other potential resources, ease stress, and decrease the sense of social isolation that was apparent after TBI. Many participants reported that
they believed these types of supports could potentially translate into more time and energy to devote to one’s partner, thereby, facilitating greater opportunities for intimacy.

It is possible that some of the participants in this study who had particular difficulty adjusting to TBI experienced pre-morbid difficulties managing stress or experienced low levels of perceived social support to buffer the challenges of TBI. Some of the partners did relate experiencing a high degree of anxiety that did not abate with time. These individuals expressed apprehension about the future more readily than couples who projected a more secure and positive outlook on their relationships. Interestingly, the struggles that some of the partners expressed seemed to be out of balance with the actual functioning or capabilities of their loved ones. Kreutzer et al. (2009) suggested that partners’ distress levels were mediated by whether or not the survivor spouses were employed or in volunteer positions. However, at least one couple in this study contradicted this notion, in that the survivor was successfully employed full-time and yet his wife demonstrated a high degree of anxiety and hopelessness about her intimate relationship. Another couple was struggling because the survivor was employed full-time at the job he had prior to his injury but after the TBI, the cognitive demands of the job exceeded his current functional skills, causing stress and tension between the couple. These accounts represent the complexity and often paradoxical nature of relationship dynamics and the value of examining topics such as these qualitatively. Instead of asking simply whether survivors were working or not, open-ended questions encouraged discussion regarding what kind of work it was and how participants experienced it. The results support the idea that experiences are not as straightforward as might be portrayed without in-depth and longitudinal explorations.

Couple well-being and adjustment in this study seemed to have a lot to do with supportive relationships and network building within their communities, such as participating in
TBI support groups or having close family members to turn to in stressful times. The problems, however, that most of the participants expressed were that they were too busy because of added responsibilities, financial pressures or lack of knowledge about community resources to establish sustained types of supportive relationships outside of their partnerships.

Peer mentor and support programs described in the literature that are designed for TBI survivors and their families (Hibbard et al., 2002; Evans et al., 2008; Struchen et al., 2011) hold promise in addressing social support and educational needs. When participants in this study were asked if they would participate in programs like these if they had the opportunity, there was unanimous agreement that they would. There is also potential to improve the ways that we prepare and provide supports to people with TBI and their partners. As some of the recent social support research indicates (Bates & Davis, 2004; Magasi & Hammel, 2004; Berkman et al., 2000; Chenoweth & Stehlik, 2004; Poortinga, 2006), we need to theorize supports in a much more complex way if we want people to genuinely benefit from them. In other words, it might be agreed that couples could benefit from collaborations with others who are experiencing similar things with the aim to develop alliances, social connections, or training seminars to increase understanding about relationships after TBI, but we need to provide the means to access these types of resources and not just expect that people will be able to use or benefit from them. Presently, survivors and partners are challenged to discover and take advantage of services due to such factors as increased family or relationship demands, financial stressors, social attitudes and misconceptions about people with TBI (Redpath et al., 2010) and a lack of communication about what services even exist (Leith et al., 2004).

Interestingly, the benefits of social support were strikingly referenced during focus groups in this research. Focus groups offered participants an opportunity to give support to each
other and they described benefitting very much from being able to talk to and meet each other. Many participants spoke of not usually having a chance to get together with other people experiencing TBI and said this was very enlightening for them. In fact, participants from both the survivor and partner focus groups agreed that having an ongoing group like this in the community would be very enticing to them and that they would definitely participate in it. It was also illuminating to observe partners talking to other partners who were more skeptical about the future with their mates. The more troubled partners said that being able to talk with counterparts was inspiring and offered them hope that things could improve.

I. **Intimacy as Multidimensional**

The fact that intimacy was conceptualized as multi-faceted by almost all participants had both positive and negative implications. On the down side, many of the components that participants identified with intimacy, such as intellectual and emotional compatibility, were compromised as a result of TBI. The ways in which couples were able to express their love and commitment to each other prior to TBI became difficult or impossible, at least in the initial stages after injury, and often permanently. Even when couples were able to reach some type of stability, partners who had been together prior to TBI consistently reported their intimacy changed. Since self-disclosure has been identified as a key factor associated with positive intimacy (Mackey et al., 2000), it makes sense that the quality of intimacy would be significantly affected after TBI. On the up side, because participants conceptualized intimacy as comprising multiple elements, it was more likely that if one area was affected, there were alternate ways of expressing intimacy. In fact, some partners talked about how they worked to reframe their concept of communication with their mates since their injuries. This is consistent with recent studies suggesting that TBI survivors and partners of survivors adopt themes of resilience and
alternative ways to express intimacy to replace feelings of loss and grief (Levack et al., 2010; Mill & Turnbull, 2004; Mukherjee et al., 2003).

J. **Societal Attitudes and Stereotypes/Misunderstandings**

When given the opportunity to talk about how they felt the public and health care professionals understood TBI, nearly all the participants described a significant lack of understanding and stereotypic treatment or attitudes regarding TBI. These negative social forces had an impact on how people identified as sexual or intimate partners. For instance, many of the survivors measured themselves against social standards of “normal” and they worried that they were not considered “real” men or women. Entrenched beliefs of health care professionals and the general public about people with TBI also may contribute to a negative sense of self for survivors (Linden & Boylan, 2010). Social gender expectations had an impact on partners’ adjustment to TBI and related changes. A few of the men partners expressed not feeling like a “man” because they could not exclusively provide for themselves and their loved ones financially and physically and therefore sought outside help. Women partners struggled with new roles and responsibilities that they assumed were “men’s” work.

Beyond gender roles, participants in this study confirmed the power of other social factors in the TBI experience for intimate couples. Many reported how other people’s reactions to TBI, including family, friends, the general public and media representations, forced them to confront and deconstruct erroneous assumptions about TBI, such as associating TBI with helplessness, tragedy or aggressiveness (Linden & Boylan, 2010). Some survivors described negative experiences with family members who covertly or overtly blamed them for their injuries either by distancing themselves or telling them that their TBI negatively affected the well-being of their families. The resentment that some families expressed further instilled
feelings of inadequacy and guilt among survivors. Similarly, many partners related situations in which families, friends or co-workers either underestimated or misunderstood their loved one’s capabilities. Some partners who met their mates after their TBI lamented that their families incorrectly assumed that they chose to be with survivors because they wanted to fulfill a caregiver need as opposed to being attracted to their mates in their own right. As a result, partners felt coerced into defending themselves and their loved ones and felt that this imposed additional strain on themselves and their relationships. They reported feeling resentment that their families or friends were unable to understand their attraction, but simultaneously felt conflicted because they also understood people’s skepticism on some levels. Redpath et al. (2010) explored the notion of professionals’ and the public’s potential prejudice towards people with TBI. Their research involved asking a sample of health professionals and the general public to rate whether they felt people were to blame or not for their injuries with hypothetical scenarios of individuals sustaining TBI as a result of drugs, alcohol, car accident or aneurysm. Both groups expressed blame and prejudicial attitudes most often when the TBI was associated with drug addiction or alcohol abuse. Findings from this study and the current research suggest that prejudicial attitudes about TBI survivors have potential to negatively impact the supports that survivors and their partners receive (Redpath et al., 2010) This supports earlier research by Nochi (1998) who identified loss in the “eyes of others” as one of multiple strands of loss experienced by people with TBI besides loss of self-knowledge and of pre-injury self. Most of the participants affirmed that loss of self-knowledge was tied into their perceptions of negative societal assumptions and lack of understanding of people with TBI.

The extent of the public’s lack of awareness of TBI was striking for a majority of partners but, especially, for partners who considered themselves fairly knowledgeable about TBI prior to
their personal experiences. Three partners who were health care professionals with varying levels of experience working with brain injury survivors described discordance between their professional and personal TBI experiences in terms of “seeing” for the first time the extent of misunderstanding of TBI by the general public. These experiences are in accord with work by Chapman and Hudson (2010) and Linden and Boylan (2010), suggesting that misunderstanding and stereotypes about TBI stem directly from lack of education and experience with TBI survivors.

Media representations of people with TBI were perceived by several participants as contributing to the perpetuation of stereotypes about TBI. Several survivors articulated their frustration with disparaging or absent media portrayals of TBI. Most partners either could not recall any portrayals of brain injury survivors in the media or, like survivors, found them to be derogatory and unrealistic.

Lack of understanding about brain injury among their families, health professionals, the general public and the media contributed to couples’ sense of isolation and lack of guidance about relationship issues. In another vein, some of the participants perceived the lack of understanding of TBI as a teaching opportunity and attempted to educate people about living with brain injury. Some also mentioned that recent political events involving American soldiers returning from Iraq with TBI helped to educate the public about brain injury and that the media should do more to educate people. Some participants also indicated that they had begun to identify with other people with disabilities and felt empowered to be part of a group of people who shared similar perspectives and social treatment. Perhaps if survivors and their partners were guided to understand the social constructions of disability, it could empower them with the knowledge to educate other people through venues such as social support or peer mentoring.
educational groups. Ultimately, the deconstruction of socially created understandings of disability, and TBI, specifically, could be instructive in terms of how interventions and community supports are envisioned.

K. **Limitations**

This study provided considerable rich data in terms of perceptions of intimacy from persons with TBI and their partners. However, the conclusions are limited because of the relatively small number of couples. The sample size is conducive of in-depth investigation but necessarily restricts the extensive exploration of various demographic and relationship characteristics that may shape perceptions of intimacy and relationship strengths and obstacles. Though the sample in the current research included a fairly diverse group with respect to factors such as age, race, ethnicity, and socioeconomic status, it is unclear to what extent the themes identified may vary depending upon such characteristics. Additionally, while vigorous efforts were made to create open, neutral interview questions, to accurately record responses, to rigorously code transcripts and to verify data analysis, there remains potential for subjective bias in interpretation of qualitative data. To address this concern, this project design included follow-up interviews with all participants and “exit” focus groups. These activities allowed for participants to expand or clarify initial responses and encouraged their feedback on the thematic analysis, which helped to validate the findings. Additionally, the principal investigator’s analysis of data was audited for bias by an experienced qualitative researcher.

L. **Recommendations for Future Research**

Future studies exploring experiences of intimacy for persons with TBI and their partners may benefit from incorporating a larger or targeted sample. This would contribute to an evaluation of the extent to which factors such as cultural, ethnic or racial background, sexual
orientation, age, gender of injured partner, socioeconomic factors, duration of time post injury, length of relationship, and whether or not the relationship predated injury determine perceptions of intimacy, relationship strengths and relationship barriers. Increasing understanding of how such variables affect relationships may contribute to health professionals’ knowledge about TBI and, thereby, increase their appreciation for critical factors to consider when working with couples.

Since change emerged prominently in this study as a complex and dynamic process, it would be illuminating in future research to gain a broader understanding of change across time, perhaps many years after TBI. This longitudinal approach would provide further understanding of whether there are specific needs for resources or supports at various stages of adjustment for couples.

There was noteworthy variability in this study regarding how well couples coped after TBI. The fact that some partners in this research reported significantly more subjective ongoing strain than other partners suggests that certain couples or individuals may be at higher risk for relationship failure. Examining the inter-relationship of pre-morbid psychological coping (Davis et al., 2009; Vangel et al., 2011), perceived satisfaction with social support, caregiving styles of couples and relationship integrity would be valuable in identifying characteristics amenable to intervention and could lead to better conceptualizations of the survival of intimacy after TBI. Interventions could then be better positioned to target potential high-risk couples in an effort to minimize or prevent relationship deterioration.

Wood and Yurdakul (1997) cited unpredictable patterns of behavior reported by partners as the most detrimental factor to the longevity and health of their personal relationships and concluded that there is a critical need to develop therapeutic interventions that assist partners to
cope with difficult behaviors. This was somewhat confirmed by the findings of this study but not in every case. Some of the partners did relate that their loved ones were verbally or physically aggressive initially after discharge home after injury. They worried about how they would get through these challenging periods, whether their relationships would withstand these times and reported they lacked any guidance in how to address these situations. However, there were a couple of instances in which survivors actually displayed more socially acceptable behaviors that marked a departure from their pre-injury selves. In each of these cases, the behaviors were unpredictable to their partners in the sense that they were uncharacteristic, even though they were considered positive changes. However, it reinforces the notion that the literature cannot be simplified into expected categories of function following TBI. Future research that adopts a multi-contextual perspective of couple functioning after TBI will help to contribute to these ideas.

In the same vein, the existing literature suggests that higher caregiver distress is associated with worse functional status of survivor partners (Kreutzer et al., 2009). However, issues of caregiver distress levels were not always neatly correlated with survivor functioning in the current study. The results in this research indicated a more complicated relationship. When examining the details of people’s relationships, post injury coping and significant reserves of strength appeared to carry many of the couples through their difficult times, in a large sense, even though challenges continued to exist. However, it was impressive to note that crises also opened up possibilities of transformation for both partners. Because this study only explored the experiences of 13 couples it would be useful to examine these concepts with larger numbers of couples in future research. Pre-morbid and post injury coping styles can be very complex. For instance, one survivor previously was emotionally and physically unresponsive and unavailable
to his family prior to his TBI. However, following his injury, he became very involved in his family’s lives, which was, although positive, difficult initially for his family to accept because it was a transformation. Another survivor was reported to be more caring (post-TBI) from his girlfriend’s perspective, and she related how this was gratifying to her but was also somewhat unnerving because it was a different side of him than she knew. Again, the complexity of TBI-related disability requires extensive and continued exploration.

M. **Implications for Clinical Application**

Health care professionals have varying degrees of understanding and experience with intimacy and TBI. It is important to increase health professionals’ and the publics’ understanding of TBI to dismantle stereotypes that contribute to poor self-esteem and other maladaptive processes that compromise intimacy. In addition, without professional support, couples often feel abandoned to find their own ways of dealing with their changes. Participants in this study were unanimous in their conviction regarding the need for more comprehensive relationship support at all stages of adjustment and the importance of professionals who possess strong knowledge, training and comfort level in addressing relationship issues.

Participants’ responses in this study helped to support the idea that faulty knowledge and lack of understanding about how to integrate families within treatment compromises not only the well-being of survivors but interpersonal relationships as well. Considering couples from this perspective sheds light on the fact that if one member of the couple is struggling, it will impact the functioning of the other partner and the relationship. Uninjured partners were an integral component in their loved one’s recovery and, at the same time, survivors deeply affected partners’ sense of selves as intimate partners. Contrary to the common perception of TBI survivors as unaware of their changes, it was clear in this study that many survivors perceived
their relationships as significantly affected by their injuries. They often were able to articulate injury related changes that contributed to relationship strain. Many survivors were active versus passive partners in their relationships. Furthermore, both partners were affected not only by the injury but by the responses of family, friends, health care professionals and society at large.

Levack et al. (2009) identified a conflict between health professionals’ acknowledgment of TBI partners as valuable to their loved ones but simultaneously considering their involvement to be potentially negative and disruptive to the overall treatment team. As a result, professionals tend to exclude partners from their loved one’s treatment program. Based on the responses in this study, it was evident that both members of the couple were affected by TBI in long lasting ways and that each member of the couple had potential to support or stress the other. The importance of intervening with caregiving partners of persons with TBI is supported by the responses in this study about partners expressing a need and desire to be an integral part of their loved ones treatment program and goals. Professionals could accomplish this by approaching couples as a partnership to help them to process and adjust to injury-related changes in their relationships and to learn about support options/opportunities. Professionals would do well to conceptualize couples as a team that can integrate their resources to cope with injury as a positive framework with the aim of bolstering and ultimately improving their relationships.

Partners’ motivation to bond together to overcome injury related challenges is a factor identified as important by many of the respondents, and it is a quality that can be encouraged by clinicians. It is also recommended that services are developed and implemented that are directed both at survivors and partners. These services could incorporate group or couples’ relationship counseling, education regarding potential impact of injury on sexuality and intimacy, education and training regarding the impact of injury on cognitive, emotional and behavioral functioning as
it relates to intimate partnerships, assistance in negotiating new roles and responsibilities, and accessing practical as well as emotional support to ease strain and fatigue, thereby, contributing to improved intimacy. In addition, some of the concepts described in the literature, such as reframing or replacing negative perceptions of loss and injury with strength based images of growth and change (Crisp, 1993; Mills & Turnbull, 2004; Mukherjee et al., 2003; Nochi, 1999) appear promising in terms of helping to shift negative perceptions of loss into reconstruction. Reframing can be based on creating or nurturing personal stories or imagining scenarios in the future in which survivors and partners successfully adjust to relationship changes. There is an emphasis on replacing negative and disempowering images with images that connote strength and hope (Mills & Turnbull, 2004; Crisp, 1993; Nochi, 1998).

As communication appeared to be an important correlate of strong intimate relationships in this study, it seems that both professional and peer support of communication would be beneficial to couples. Additionally, formal training targeting expressive and receptive communication skills of survivors along with counseling to address effective communication skills between partners could be helpful. These services would be beneficial within individual, couple or group formats. Recommendations such as making communication the main focus of couple’s therapy and helping partners develop techniques to adapt to lifelong changes is supported by more recent research (Blais & Boisvert, 2007).

Since this study revealed that certain couples experienced increased relationship fragility and more difficulties accepting changes than other couples, targeted interventions might help to mitigate stressors. Options include stress management training and psychological counseling to identify adaptive ways to accept changes and manage increased roles. Many participants in this study also noted a scarcity of resources to help with practical responsibilities that contributed to
relationship strain. Fatigue and stress had a deleterious effect on intimacy. Assistance finding personal care assistants to provide caregiving or homemaking services, such as grocery shopping or babysitting, could give couples more time to spend with each other and significantly lessen fatigue. Connecting couples to disability advocacy organizations in the community to assist in accessing additional resources could help to empower people by creating social support networks.

It is noteworthy that every participant in this study reported having no relationship or intimacy services during any phase of their health care experience. The majority of participants agreed that these services would have benefitted them. Conventional rehabilitation services routinely focus on improving cognitive and other physiological functioning, with the assumption that improvement in these areas will generalize to real-life activities and skills. The complexities of relationships make it unlikely that an emphasis on improving injury-related problems will automatically translate into improved intimate relationships.

A specific focus on negotiating intimate relationship issues should be incorporated into all TBI rehabilitation programs. Services targeted towards both survivors and their partners could offer group or couples’ relationship counseling and education regarding the impact that behavioral, emotional or cognitive changes may have on intimate relationships. Education regarding the potential effects of injury on sexuality as well as guidance in negotiating new roles and responsibilities should also be a consistent component of rehabilitation intervention.

Traditional cognitive interventions that are integral components of speech, psychological and occupational therapy could integrate relationship issues by focusing on social communication skills. It would be enlightening to have significant others’ input into goal setting so that relationship issues are more likely to be relevant to each couples’ situations and needs.
All levels of rehabilitation, including inpatient, outpatient and community day programs would benefit from including intervention or educational protocols for intimacy and relationship issues, counseling and educational supports and resources.

Health care professionals can introduce intimacy topics in a general way at the earliest acute stages of injury. They could provide education and an opportunity for further exploration and assistance when survivors, partners or couples are ready, as different stages of recovery will vary.

In an attempt to facilitate these recommendations health care professionals need to feel comfortable and gain experience with intimacy and TBI. Otherwise, couples may have to resort to struggling to figuring things out themselves with little guidance or support. For these reasons, it is critical for health care professionals to have education and training to increase knowledge, skills and comfort level addressing relationship and intimacy issues with couples. The sexuality training and education sessions for health professionals described by Simpson et al. (2006) and Vaughan (2009) were reported to significantly contribute to professionals comfort level with discussing sexuality and intimacy issues with their clients.

One caveat regarding couples counseling for partners with TBI is that, although many participants in this study recommended that healthcare professionals initiate topics of intimacy, many professionals may not be qualified to address these issues, even after training. Intimacy counseling is complex in its own right but even more challenging within the context of TBI. For these reasons, it might be most appropriate for healthcare professionals to focus on becoming informed about relevant resources in the community for couples to access, such as peer mentoring or support groups or other advocacy or disability related community organizations. It is conceivable that intimacy issues might be effectively addressed in groups where other people
experiencing similar issues can provide support or guidance that could facilitate positive changes for couples. Healthcare professionals may best serve couples by checking up with them at various stages to get a sense about how they are faring and to inquire whether they feel they have appropriate or adequate resources.

N. **Summary**

In summary, this study adds depth to current TBI and relationship research because of the detail and variability of participants’ responses. The dynamic ways in which each partner influences the other has implications for how we conduct future intimacy research. Since this study explored participants’ intimacy experiences over a specified period of time, it was enlightening to learn how intimacy and relationship issues are, in fact, fluid and complex. Our understanding of the specific factors that contribute to these changes will benefit from further investigation.

The most current relationship research supports the notion that intimate relationships after TBI are of critical importance to the well-being of both partners (Godwin et al., 2011; Hammond et al., 2011). It seems prudent, then, for health care professionals to conceptualize both members of a couple as a cohesive team that can combine their resources and adjust to injury related changes together. Clinician support of such a collaborative model can be instrumental in bolstering and ultimately strengthening intimacy. This type of support is relevant both in inpatient and outpatient rehabilitation settings and at the community level in order to provide a broad network of services over the long-term.

In re-visiting the research questions that guided this study, the following findings should be highlighted:
1. How does the experience of TBI affect intimate relationships of TBI survivors and their significant others?

TBI can be a profoundly life-altering experience that affects intimate relationships in complex and dynamic ways. Changes related to cognitive and physical functioning present significant challenges to intimacy, but many variables not directly related to the brain injury itself affect the endurance and quality of intimate relationships after TBI.

2. What does intimacy mean to each individual in the aftermath of TBI?

Intimacy, for the most part, mirrored what most couples valued. There were a couple of participants who felt intimacy represented primarily physical or sexual relations, but these ideas were in the minority. Intimacy was all-encompassing for most participants.

3. What factors lead to positive or negative relationship outcomes? What are the barriers or facilitators or supports that make a difference in the experience of intimacy?

Factors leading to positive relationship outcomes include pre-injury positive relationships, support of family and friends, good communication, both partners supporting and expressing their love to each other, sense of spirituality, and a commitment to make things work and to adjust to permanent and transformative change.

Factors leading to negative relationship outcomes include inadequate communication, lack of social support, increased partner responsibility, decreased income, survivor’s cognitive or behavioral changes, survivor not expressing love or support to partner, survivor feeling guilt, shame or letting partner down, and lack of professional services and resources.

4. How do survivors’ and uninjured partners’ experiences compare and contrast with each other?
Both survivor and partners expressed the importance of good communication and supporting each other as factors important to good intimacy. Both groups also reported significant loss of friends, social interaction and change of roles and responsibilities.

Survivors and partners differed in their conceptualization of change. Survivors felt that real change, such as improved communication, developed with time, but partners admitted to consciously making an effort to accept changes and adapt to new ways of communicating with their survivors.

5. How is the experience of the intimate relationships stable or changing for both partners, and what factors contribute to that stability or change?

The experience of intimacy after TBI was both stable and changing for partners. Most partners shared a sense of transformation of their relationships and themselves as a result of TBI. However, some uninjured partners seemed to have a more difficult time with adjustment, even after factors such as survivor impairments, time since injury and other variables were taken into account, suggesting a correlation between partner pre-injury coping and post TBI adjustment.

6. How is identity as an intimate partner after TBI affected for survivors and partners?

Most survivors struggled to feel sexual or attractive after their injuries as a result of physical, cognitive or emotional changes. Many of the challenges that survivors grappled with seemed to reflect society’s stereotypes of who is considered attractive and sexual. Most partners expressed feeling challenged with simultaneously negotiating caregiver and intimate partner roles.

7. How do social reactions from significant others and family members, acquaintances, professionals, and media images affect intimacy experiences after TBI?

Many survivors had difficulty feeling as though they were attractive enough or able to perform up to society’s standards of an intimate partner. Internalization of the media’s negative or absent
portrayals of people with disabilities contributed to negative self-images for many survivors. Family and friends’ assumptions about why a partner chooses to stay in a relationship with the TBI survivor can add additional negative pressure.

8. What recommendations do survivors and partners suggest for improved clinical and community supports that are helpful to their adjustment process?

All participants recommended that healthcare professionals increase their knowledge about TBI survivors and intimacy issues, specifically. They were unanimous, as well, in terms of feeling that intimacy supports and services should be available at all stages of adjustment. Many participants felt that uninjured partners needed to be integrated more formally and consistently in their loved ones’ treatment programs, that the couple should be acknowledged as a team needing support, and that professional follow-up for couples should continue for many years post TBI.
VII. CITED LITERATURE


APPENDICES

APPENDIX A - ORIGINAL IRB APPROVAL

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Initial Review (Response To Modifications)

November 3, 2005

Carol J. Gill, PhD
Disability and Human Development
236 DHSP
M/C 626
Chicago, IL 60612
Phone: (312) 355-0550 / Fax: (312) 996-7743

RE: Protocol # 2005-0338
“Exploring Intimacy Following TBI”

Dear Dr. Gill:

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on October 27, 2005. You may now begin your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: October 27, 2005 - August 3, 2006
Approved Subject Enrollment #: 48
Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.
Performance Sites: UIC
Sponsor: National Institute on Disability & Rehabilitation Research

Research Protocol: Exploring Intimacy Following TBI
APPENDIX A (continued)

**Recruitment Materials:**
- a) Flyer, Exploring Intimacy following TBI, Version #1, 5/25/05
- b) Telephone Script for screening volunteers, version #1, 7/20/2005
- c) Re-Contact Script, no version #, submitted 7/21/05

**Informed Consents:**
- a) Exploring Intimacy following TBI, TBI, FG, version #3, 9/29/05
- b) Exploring Intimacy following TBI, Signif. FG, version #3, 9/29/05
- c) Exploring Intimacy following TBI, Guard. FG, version #3, 9/29/05
- d) Exploring Intimacy following TBI, TBI Inter. version #3, 9/29/05
- e) Exploring Intimacy following TBI, Signif. Inter. version #3, 9/29/05
- f) Exploring Intimacy following TBI, Guard. Inter. version #3, 9/29/05
- g) Exploring Intimacy following TBI, Reaffirmation of Consent, version #2, 9/29/05

**Assents:**
- a) Exploring Intimacy following TBI, FG Assent, version #3, 9/29/05
- b) Exploring Intimacy following TBI, Interview Assent, version #3, 9/29/05

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category:

(FCR) Research has been determined to be no greater than minimal risk by the convened IRB and requires convened Continuing Review.

Please note the Review History of this submission:

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Please remember to:

- Use your research protocol number (2005-0338) on any documents or correspondence with the IRB concerning your research protocol.

- Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.
APPENDIX A  (continued)

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 413-2053. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sophia L. Radlowski, M.Ed
IRB Coordinator, IRB # 2
Office for the Protection of Research

Subjects

Enclosures:

1. UIC Investigator Responsibilities, Protection of Human Research Subjects

2. Informed Consent Documents:
   a) Exploring Intimacy following TBI, TBI,FG, version #3, 9/29/05
   b) Exploring Intimacy following TBI, Signif.FG, version #3, 9/29/05
   c) Exploring Intimacy following TBI, Guard. FG, version #3, 9/29/05
   d) Exploring Intimacy following TBI, TBI Inter. version #3, 9/29/05
   e) Exploring Intimacy following TBI, Signif.Inter. version #3, 9/29/05
   f) Exploring Intimacy following TBI, Guard.Inter. version #3, 9/29/05
   g) Exploring Intimacy following TBI, Reaffirmation of Consent, version #2, 9/29/05

3. Assent Documents:
   a) Exploring Intimacy following TBI, FG Assent, version #3, 9/29/05
   b) Exploring Intimacy following TBI, Interview Assent, version #3, 9/29/05

4. Recruiting Materials:
   a) Flyer, Exploring Intimacy following TBI, Version #1, 5/25/05
   b) Telephone Script for screening volunteers, version #1, 7/20/2005
   c) Re-Contact Script, no version #, submitted 7/21/05

5. Optional Form 310 - Protection of Human Subjects, Assurance Identification/Certification/Declaration (If federally supported)

cc: Tamar Heller, Disability and Human Development, M/C 626
# APPENDIX B - IRB APPROVAL FOR ADDITIONAL ANALYSIS

## Approval Notice

Initial Review (Response to Modifications)

February 13, 2012

Carol J. Gill, PhD  
Disability and Human Development  
1640 W. Roosevelt Road  
236 Idd, M/C 626  
Chicago, IL 60612  
Phone: (312) 355-0550 / Fax: (630) 920-0928

**RE:** Protocol # 2012-0083  
“Exploring Intimacy Following TBI (re-submission of UIC# 2005-0338)”

Dear Dr. Gill:

Your Initial Review (Response to Modifications) was reviewed and approved by the Expedited review process on February 9, 2012. You may now begin your research.

Please note the following information about your approved research protocol:

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Recruitment Material(s):

  d) No recruitment materials will be used

Informed Consent(s):

  h) Exploring Intimacy following TBI, Reaffirmation of Consent; Version 2; 09/29/2005
  i) Waiver of Signed Consent Document granted under 45 CFR 46.117

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes. (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

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<td>Response to Modifications</td>
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<td>02/09/2012</td>
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Please remember to:

➔ Use your research protocol number (2012-0083) on any documents or correspondence with the IRB concerning your research protocol.

➔ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.
APPENDIX B (continued)

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Marissa Benni, M.S.
IRB Coordinator, IRB # 2
Office for the Protection of Research

Subjects

Enclosure(s):

6. UIC Investigator Responsibilities, Protection of Human Research Subjects
7. Informed Consent Document(s):
   h) Exploring Intimacy following TBI, Reaffirmation of Consent; Version 2; 09/29/2005

cc: Tamar Heller, Disability and Human Development, M/C 626
    OVCR Administration, M/C 672
VITA
Nina Robins

Home: 31 Elm Street
       Winchester, MA 01890
       (215) 850-4364
       robinsnina@gmail.com

Work: Spaulding Rehabilitation Hospital
       125 Nashua Street
       Boston, MA 02114
       (617) 573-2931

EDUCATION
University of Illinois at Chicago (UIC), Chicago, IL
Disability Studies Ph.D. Program, Department of Disability and Human Development
Dissertation title: “Exploring Intimacy after Traumatic Brain Injury (TBI) for TBI survivors and their partners”
Expected graduation: May, 2012

Tufts University, Medford, MA
Boston School of Occupational Therapy (BSOT), M.A., Occupational Therapy, 1988

Ithaca College, Ithaca, NY
B.S., English and Sociology, 1979

CERTIFICATIONS/ AFFILIATIONS
Clinical Scholars Program
Spaulding Rehabilitation Institute, Boston, MA
November 2011-present

Disability Ethics Scholar
Rehabilitation Institute of Chicago, Chicago, IL
Jan 2003-present

Assistive Technology Fellowship
Spaulding Rehabilitation Hospital, Boston, MA
May-October, 2001

Disability Ethics Scholar
Center for the Study of Disability Ethics
Rehabilitation Institute of Chicago, Chicago, IL
May 1999-present
Assessment of Motor and Process Skills (AMPS)
Chicago, IL
September, 1995

NDT/Bobath
San Diego, CA
3 week course in the treatment of adults with stroke
February, 1994

PROFESSIONAL EXPERIENCE

Spaulding Rehabilitation Hospital, Boston, MA
Advanced Occupational Therapist, 32-40 hrs/wk.
Evaluation and treatment of inpatients with various physical conditions including stroke, traumatic brain injury, orthopedic injuries, burns, and other medical diagnoses. September 2010-present

Brigham and Women’s Hospital, Boston, MA
Occupational Therapist, Per Diem, 8-32 hrs/wk. Responsibilities include evaluation and treatment of inpatients with various physical conditions ranging from stroke, TBI, orthopedic injuries, burns, heart and lung transplants and other medical diagnoses. Initiating mild traumatic brain injury (MTBI) research identifying people who sustain long-term post-concussive syndrome for improved services, 2006-present

The Rehabilitation Institute of Chicago, Chicago, IL: Occupational Therapist-Registry, Per-Diem.
Provided evaluation and treatment in outpatient and inpatient traumatic brain injury, stroke, spinal cord injury, amputee, orthopedic and burn units, 2003-2006

University of Chicago at Illinois, Dept. of Disability and Human Development, Chicago, IL.
Graduate Research Assistant, 10 hours/wk.
Responsibilities included literature searches and reviews related to disability studies, assisted in coordination of disability related events and general office tasks, 2003-2006

Community Rehabilitation Care, Inc. (CRC), Newton, MA.
Occupational Therapist and Case Manager
Provided evaluation, treatment and case management for clients with traumatic brain injury (TBI) and stroke diagnoses in a community reintegration center. Caseload consisted of 7-20 clients. Designed and implemented a pre-work skills group for TBI clients. Case management responsibilities included: insurance authorization for
treatment and community services, coordination of home and community disability related services, comprehensive continuum of care services from community day services to full community inclusion during and following rehabilitation discharge, client and family training and disability awareness teaching modules. Provided specialized home treatment services as indicated. March 2002-December 2002

**Spaulding Rehabilitation Hospital**, Boston, MA.
Senior Occupational Therapist, Traumatic Brain Injury unit.
Assisted practice leader with program development, clinical training to seven staff occupational therapists and two rehabilitation aides, performed assistive technology evaluations and treatment, designed and implemented peer mentor volunteer program, brain injury community reintegration group in collaboration with recreational therapist, and functional tasks for TBI model systems research data collection, daily evaluation and treatment of inpatients with TBI. February 2001-March 2002

**Beth Israel Deaconess Medical Center (BIDMC)**, Boston, MA
Registry Occupational Therapist, 24 hrs/wk.

**Winchester Nursing Center**, Winchester, MA.
Registry Occupational Therapist, 16 hrs/wk.
Evaluation and treatment on rehabilitation unit for elderly adults with neurological and orthopedic diagnoses. October 2000-February 2001

**Rehabilitation Institute of Chicago--Day Rehabilitation Center**, Willowbrook, IL.
Staff Occupational Therapist
Clients included adults and children with primarily neurological diagnoses. Developed and implemented community intervention model for the following programs: Disability Awareness and Community Resource Support group in collaboration with director of DuPage Independent Living Center, work/volunteer skills group, Special Recreation animal care and therapeutic riding program in collaboration with local stables, community gardening group, computer training program (in partial fulfillment of stroke research grant). January 1997-October 2000
Rehabilitation Institute of Chicago, Chicago, IL
Staff Occupational Therapist
Evaluation and treatment on stroke and traumatic brain injury inpatient floors. Involved in program development for interdisciplinary treatment model of stroke/head injury unit. Supervised Level II fieldwork students. Developed and piloted OTR/COTA partnership model. Co-instructed new staff NDT module. Received Buchanan award for research implementation of AMPS evaluation at home and in clinic for persons with stroke. April 1995-January 1997

Boston University Medical Center, Boston, MA
Senior Occupational Therapist
Clinical supervision of three occupational therapists. Evaluation, treatment, and supervision of staff on acute neurosurgical/neurology, cardiothoracic and general rehabilitation units. Team therapist on outpatient ALS center. Developed outpatient pulmonary rehabilitation program. Implemented collaborative learning approach with multiple level II students and entry level staff. October 1993-March 1995

Lahey Clinic Medical Center, Burlington, MA
Staff Occupational Therapist, October 1990-October 1993

New England Rehabilitation Hospital, Woburn, MA
Staff Occupational Therapist, September 1988-October 1990

Boston Veteran’s Administration Medical Center, Boston, MA
Staff Occupational Therapist, January-September 1988

Inc, Magazine, Boston, MA
Editorial and Publicity Assistant, 1984-1986

Little Brown and Company, Boston, MA
Editorial Assistant, 1981-1984

Plays and the Writer, Boston, MA
Customer Service Assistant, 1980-1981

Wordsworth Bookstore, Cambridge, MA
RESEARCH

“Exploring Intimacy and Sexuality after Traumatic Brain Injury (TBI).” RRTC in collaboration with University of Illinois at Chicago and Texas Medical Center and Rehabilitation in Houston, Texas, 2003-present

“Peer Mentorship in Traumatic Brain Injury: A Disability Identity Perspective” (in progress), Senior Ethics Scholar research project, Ethics Scholar Program, Rehabilitation Institute of Chicago

“Computer Training Program for Persons with Stroke” RIC Clinician-Research and Rehabilitation Research Center (RRTC) (October 1998)


“Therapeutic Horseback Riding: A Treatment Intervention to Improve Sitting Balance in Two Children with Cerebral Palsy,” Tufts University, Master’s Thesis (June 1998)

HONORS

Sarah Baskin Award for Excellence in Research, Rehabilitation Institute of Chicago (1998)

Stroke Grant: RIC Clinician-Researcher and Rehabilitation Research Center (RRTC) (1998)

PUBLICATIONS

“Home vs. clinic on IADL performance of patients with stroke,” OT Practice, Aug. 1998

“Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners,” Journal of Head Trauma and Rehabilitation, 26(1) 1:56-68, Jan/Feb 2011
PRESENTATIONS


“Promoting Self-Representation in Film for People with Traumatic Brain Injury,” Film & the Problem Body: A Symposium on Disability in the Movies,” University of Calgary, Calgary, Canada (January 2005)

“Assistive Technology Evaluation and Intervention for Persons with Traumatic Brain Injury (TBI),” Brain Injury Team In-Service Series, Spaulding Rehabilitation Hospital, Boston, MA. (March 2002)


“OTR/COTA Collaborative Partnership Model.” Stroke Rehabilitation: COTA Course, Rehabilitation Institute of Chicago, Chicago, IL (March 1998)

“Cognitive and Perceptual Considerations in the Brain Injured Adult,” Stroke Rehabilitation: COTA Course, Rehabilitation Institute of Chicago, Chicago, IL (March 1995)

ASSOCIATIONS

Society for Disability Studies (SDS)
American Occupational Therapy Association (AOTA)