Patterns of Occupational Engagement Pre- and Post- Partner’s ABI

June, 2011

This research, submitted by Adam Whaley, has been approved and accepted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy from the University of Puget Sound.

Committee Chairperson: Ron Stone

Reader #1: Tatiana Kaminsky

Director, Occupational Therapy Program: George Tomlin

Dean of Graduate Studies: Sarah Moore
Abstract

This study examined the pre- and post-injury patterns of occupational engagement for a partner of a man with ABI six years post-injury. The participant was a 64 year old white woman who is referred to by the pseudonym of Olivia. She and Joey (pseudonym) had been married for 17 years pre-CVA, and were still married 6 years post-CVA. Due to the impact of Joey’s CVA on the relationship, Olivia experienced an increase in the demand from her occupational environment in order to remain in her role as Joey’s wife which also impacted Olivia’s pre-injury patterns of engaging in occupations. Three main themes illustrated the changes in her patterns of engaging in occupations: (1) cessation, (2) accommodation, and (3) initiation. The increase in caregiver responsibilities placed on Olivia impacted several areas of engagement. She experienced decreases in time she could spend with friends, work, activities she and Joey did together, times traveling to her cabin, and time with her grandchildren. She stopped several activities like baseball and hiking, and started watching television with Joey, and occasionally falling asleep on the couch. Her desire to master the role of Joey’s wife was strong and supported by several factors, such as length of relationship pre-injury, Joey’s level of function, and being older adults.
Patterns of Occupational Engagement Pre- and Post- Partner’s ABI

Engaging in occupations such as leisure, work, play, social participation, activities of daily living (ADLs), and instrumental activities of daily living (IADLs) contributes to the formation of a healthy sense-of-self (Hocking, 2009). Factors that influence engagement in occupations are stressors, responsibilities, or life circumstances. These influences may affect the current occupational role an individual assumes, such as being a life partner (Crepeau & Schell, 2009).

According to Robins (2010) in *Exploring Intimacy: Cultivating healthy relationships through insight and intuition*, there are no guidelines in fostering relationships and what is needed is “both trust and clear communications to form healthy balanced partnerships” (Robins, 2010, p. 42). Every relationship is unique and creating a balance in the roles of each partner and their ability to obtain a healthy sense-of-self can be difficult. Roles in a life partnership may include breadwinner, protector, nurturer, and housekeeper. To fulfill these roles each partner engages in occupations such as work, social participation, and education (Roley et al., 2008) to meet the demands of the role and also maintain personal well-being.

Maintaining a balance between partners’ roles can be difficult. When challenges cause a disruption in established roles the new demands placed on partners may influence their roles and their ability to engage in previous occupations. Such a challenge may arise when one partner is injured, such as with acquired brain injury (ABI).
Acquired brain injury is a term used for injuries to the brain that occur after birth. For the purpose of this study, ABI will refer to stroke (CVA) and traumatic brain injury (TBI). The Centers for Disease Control and Prevention (CDC) have estimated that each year 1.7 million people in the United States (U.S.) have a TBI with 275,000 being hospitalized (CDC, 2006), whereas 795,000 people in the U.S. will have a stroke each year (CDC, 2010).

Survivors, or individuals with the ABI, may demonstrate psychological changes (Minnes, Graffi, Nolte, Carlson, & Harrick, 2000, p. 737), physical changes (Peters et al., 1992), and alterations in socio-emotional functioning (Burridge, Williams, Yates, Harris, & Ward, 2007) as a result of their brain injury. These changes may impact the balance of roles within the survivor’s relationship and subsequently, the ability of his or her partner to engage in previous occupations such as leisure, work, play, social participation, ADLs, and IADLs (Roley et al., 2008). For example, survivors tend to withdraw from social environments which may include group activities the couple enjoyed doing together. This, in turn, may affect their partners’ opportunities to establish new friendships and continue involvement in previous leisure and social activities the two of them once shared (Wood, Liossi, & Wood, 2005).

Background

Studies on the impact of ABI on relationships have focused on marriages and report variable results. Divorce rates 2 to 15 years post injury have been reported as ranging from 15% to 78% (Godwin, Kruetzer, Arnogo-Lasprilla, &
Kreutzer, Marwitz, Hsu, Williams, and Riddick (2007) studied marital stability after ABI and found that 75% of the couples in their study (N = 120) were still married four years post-injury. Predictors of stability in marriage for this sample were age (older individuals had higher rates of stable marriage), and time together pre-injury, $M = 16.5$ years, $p < .05$, with couples that had been together longer more likely to stay married post-injury, $F_{1, 97} = 14.41$, $p < .001$. In another study, Arango-Lasprilla et al. (2008) reported that 82-88% of couples (N = 977) remained married two years after a TBI, and risk factors for separation were younger age and the partner with TBI being male.

In addition to studies on the sustainability of relationships post ABI, researchers have also explored outcomes for spouses who assume the role of primary caregiver. In Kreutzer, Gervasio, and Camplair’s (1994) study, participants (N = 62, n = 34 spouses or live in partners, n = 28 parents) completed two surveys (Brief Symptom Inventory (BSI) and the Family Assessment Device (FAD)) that assessed the impact on caregivers when a family member had a TBI. The responses on the BSI survey indicated that 33% of caregivers had high scores on the Paranoid ideation subscale, $t(55.9)$, $p < .05$, which includes feelings of irritability, resentment, depression, being taken advantage of, and anxiety. One-fourth reported high scores on the Hostility subscale, $t(55.9)$, $p < .05$, that manifested as getting into frequent arguments and feeling like breaking things. Kreutzer et al. (1994) also stated that symptoms of ABI stressed the “sexual relationship and all it symbolizes” (p. 207) and caused the loss of a “reciprocal
relationship” (p. 207). Some of the specific factors that can impact the relationship and the partner after a person has ABI are the survivor’s level of functioning, ability to socialize, and the extent of time that the survivor needs on-call support.

**Level of function.** In a study by Eriksson, Tham, and Fugyl-Meyer (2005) exploring couple’s happiness and life satisfaction from 1 to 5 years post-injury, pairs of questionnaires were sent to individuals with TBI ($n = 92$) and to people close to them. Of the people close to the individuals with TBI, 55 were partners (co-habitating or married) and 37 were friends and family. The researchers reported an increase in perceived satisfaction that correlated with a decrease in reported impairments, problems, or level of assistance needed with activities. Life satisfaction for the couples was tied to the ability of the survivor to wash clothes (partners were 9.5 times more likely to be unhappy if the survivor had problems with this activity, $p < .003$, 95% CI [2.2, 48.2]), make contact with others (6.3 times more likely to be unhappy, $p < .02$, 95% CI [1.4, 31.1]), and enjoying leisure time (5.1 times more likely to be unhappy, $p < .04$, 95% CI [1.1, 25.5]).

The impact of the survivor’s level of functioning in occupations on the ability of the partners to adjust to the new dynamics of their marriage was explored by Peters et al. (1992). The researchers examined marital adjustment from the view of the survivor’s wife. These wives ($N = 48$) reported less expressed affection, lower satisfaction and feelings of cohesiveness, and an inability to adapt to the changes in the partnership dynamics at 1 to 10 years
post-injury. Successful adaptation was linked to functional independence of the survivor.

**Social life.** Effects of ABI on psychosocial functioning of the survivor can impact the relationship with the survivor’s life partner. Peters, Stambrook, Moore, and Esses (1990) explored the psychological effects of ABI and the impact on the spouse. Survivors’ spouses \((N = 55)\) revealed that the severity of the brain injury, economic pressure, and inability to adjust socially were related to decreases in marital adjustment and the display of intimate feelings.

Another study looking at the effects of ABI on the spouse was done by Wood et al. (2005). They examined marital satisfaction and adjustment from the view of the spouse of an individual with a brain injury. Researchers studied two groups of spouses \((N = 48)\), in one group the partners were still together \((n = 25)\), in the other group the partners were separated \((n = 23)\). Couples were interviewed five years post-injury on average. Both groups reported that the client’s unstable behavior (social disinhibition, mood swings, lack of motivation) was the biggest contributor to their dissatisfaction with the relationship. Another consideration noted in both groups was the proclaimed ‘social limbo’ (unbalanced relationship and reduced chances to foster new friendships) that spouses said they experienced as a result of the injured partner.

**On-call.** Poulin, Brown, Ubel, Smith, and Langa (2010) explored the differences in levels of well-being reported by caregiver spouses \((N = 73)\) when providing active assistance to their partner or by being on-call (waiting to
provide help). Their study indicated a strong correlation between providing direct assistance, such as assisting in eating when the partner had a high level of interdependence, and the caregiver spouse reporting positive effects on well-being ($\beta = .17, p = <.01$). In addition, results from the study also indicated that the moments the caregiver spouse spent waiting on-call correlated with negative effects on his or her well-being ($\beta = -.10, p = < .05$). This study supports the importance of actively providing assistance as a positive reinforcement to well-being and the need for the caregiver to minimize time spent waiting by engaging in meaningful activities.

Partners of survivors have to adapt to the changes caused by the ABI to maintain a healthy sense-of-self. These changes may result in acquisition of new roles and occupations for partners, such as that of caregiver, and loss of other roles and occupations. The link between occupation and life satisfaction is described by Yerxa (1998), when she said that “opportunities for active engagement in life contributes to health, well-being, independence, and survival” (p. 417). Current literature does not provide direct examples of the impact of ABI on the partner’s ability to engage in occupations with the exception to those related to the caregiver role. Further research is needed to explore effects of ABI on the partner’s ability to engage in occupations. This study will examine the pre- and post-injury patterns of occupational engagement for partners of people with ABI five or more years post-injury.

**Method**
Participant

Approval by the Institutional Review Board (IRB) at the University of Puget Sound was obtained before any recruitment of participants took place. To be included in the study, participants had to be the partners’ of the survivor, speak English, live in the Tacoma or Seattle area, and be over the age of 25. The partner also needed to be currently in a relationship with the survivor. Partners could be currently living with the survivor or living separately. Length of the relationship needed to span six months or more pre-injury to more than five years post-injury. Exclusion criteria included the participants taking anti-depressants and the survivors having a diagnosed mental illness. One participant was recruited for this study. She was recruited from a support group in Tacoma, WA. Before the initial interview, the participant signed a consent form to participate in the study and to have the interview audio recorded.

The participant was a 64 year old white woman with some college experience who is referred to by the pseudonym of Olivia. She had been married to her partner, who is referred to as Joey, for 23 years. Both Olivia and Joey had two children from previous marriages and had six grandchildren. They were married for 17 years before the injury, and at the time of the interviews, 6 years post-injury, were still married and lived together. Joey had a left CVA 6 years prior to the study and did not present with the typical physical symptoms of a stroke. Olivia said “if you look at him you wouldn’t know,” but he did develop
expressive and receptive aphasia and had vascular dementia. Joey was 70 years old and had a college degree.

**Data Collection**

Two one-hour interview sessions were conducted in consecutive weeks on the same day and time of the week. Each session was held in a private room on the university campus. Olivia filled out a demographic information form providing information such as age, sex, date of partner’s injury, degree of partner’s injury, cause of partner’s injury, education level of both partners, and time in relationship pre- and post-injury (see Appendix A for form). Each interview was recorded and transcribed.

Interviews were semi-structured and followed an interview guide (see Appendix B) created by the researcher in collaboration with experienced researchers and using examples from published qualitative articles. A pilot interview was conducted prior to the first interview to refine questions. The opening question of each interview was a grand tour question (e.g., “Tell me about the activities that you were involved in before your partner’s injury?”), as suggested by Spradley (1979), and follow-up questions (see Appendix B) were used to guide the informant to further explore different topics. Sessions were recorded by digital recorder, transcribed, and coded to generate themes. Notes were taken during interviews to refer to non-verbal cues or to mark changes in tone and expressions.
Analysis of interviews began at the end of the first interview and continued until the final report was complete. Transcripts and audio-recordings from the first interview were analyzed to identify themes and generate additional follow-up questions for the second interview. The second interview explored the topics mentioned in the first interview in further detail whenever necessary. Total time between first contact with the participant and the second interview was one week.

Data Analysis

Data analysis included content analysis through coding the interviews (Portney & Watkins, 2008) and creating meta-data (data about data) (Kielhofner, 2006) such as data matrixes and concept maps. Transcripts were analyzed and descriptive conceptual labels (index coding) were applied as necessary. Conceptual labels were used to consolidate the passages based on particular topics. Meta-data were also created using the computer program Inspiration. Preliminary themes were entered into the program to find relationships and overarching concepts using bubble mapping techniques. A code directory was developed to consolidate codes and streamline the retrieval process in a systematic and consistent way. Through this process, themes were generated to complete the data analysis.

Rigor

To increase the rigor of this study the interviews were recorded digitally, transcribed, and a 20 minute telephone session was conducted to perform
member checking. A copy of all documents without any identifying information was organized by unique identifiers and kept in a master file (Kielhofner, 2006) to create an audit trail and maintain validity of the findings (Portney & Watkins, 2008).

Data analysis procedures and results were discussed with experienced researchers. To improve accuracy of data analysis, the researcher kept track of how many times the recordings and transcripts were reviewed, and amount of time spent re-examining the data.

**Results**

Results from analysis of both interviews revealed a shift in Olivia’s role as a wife. Three main themes also emerged depicting her engagement patterns in occupations pre- and post- Joey’s CVA. These three themes are: (1) cessation, (2) accommodation, and (3) initiation.

**Role Shift**

Olivia’s role as wife pre-injury was established within the structure of her relationship with Joey as being mutually interdependent. Her description of a typical day pre-injury was that “we just got up, and got dressed, and had breakfast, and went to work, and came home, and had dinner…did housework, and…shared that together.” During dinner they connected by talking “about our day, and how it went… sometimes about family….maybe talk about anything that came in the mail…discuss: maybe insurance papers…talk about the kids; talk about plans that we would like to make to do things.” These talks and
additional times they had together at night, were the only moments in the day that Olivia mentioned they had together without being in a “dead run.”

After Joey’s CVA, the balance of the relationship changed and Olivia’s role as wife was redefined. She now had to provide assistance to Joey to help him meet his needs in addition to maintaining her engagement in meaningful activities needed for a healthy sense-of-self. Olivia expressed that she felt like she was “caged in the circumstances…you know, the 24/7: you're just on-call 24/7. And I didn't mean that to sound disrespectful, it's just…you feel like you’re trapped in this world that you can’t – can't get out of.” Furthermore, she was uncomfortable leaving him alone for more than four to five hours a day, because if “something should happen, like…if he were to have a stroke or fall down…I want to be home.” Having to watch over him and double check what he was doing, because he was “forgetting steps,” placed Olivia in a position of a supervisor to Joey, compounding her role as a partner.

The new burden placed on her to get Joey to appointments, to support groups, help him with his “therapy homework,” and the desire to engage him and avoid having him feel like he is a “burden,” has limited her ability to have time for herself. Despite feelings of being “caged,” she continues to strive to maintain her role as Joey’s wife because she feels that the constant push “beats the alternative…God just blesses us and we get through.” The shift in the balance of responsibilities in the relationship forced Olivia to adjust to the changing demands placed on her in order to continue her role as Joey’s wife.
Patterns of Engagement in Occupations

Olivia’s patterns of engaging in occupations were influenced by the effects of Joey’s CVA, an increase in time spent supporting Joey, lack of support from family, and feeling pressed to enjoy time with Joey because of his declining health. The impact of Joey’s injury on Olivia’s engagement in previous occupations led to the cessation, accommodation, or initiation of several activities.

**Cessation.** Olivia stopped engaging in several activities in leisure, play, and social participation after Joey’s CVA.

**Play.** She stopped playing baseball after Joey’s CVA and stated that “if…circumstances were different. I would love to play on a slow pitch team again…I really miss it. I’d rather do that than eat; I loved it.”

**Social participation: Friends.** Olivia also ceased her overnight trips with her girlfriends to a cabin in the area because “nobody’s ever offered to keep him overnight.” She also ceased going to “girlie movies,” due to difficulty finding someone to watch Joey.

**Leisure.** The hiking activities Olivia shared with Joey had ceased because “he doesn't have good balance anymore. And…his walking is - is pretty unstable at times.” Boating had also stopped because they “sold the boat, so that's out.” In addition, talking at the dinner table in-depth about daily events and plans ceased because “communication is really a problem… if I get in to too long of a
dissertation, he – I think he loses me – so. It’s hard to have a one-way conversation.”

In addition, before the CVA, if Joey was gone Olivia would put music on when performing her chores because “I love music. When Joey’s not home I will play music.” Now she’s with Joey “24/7” and the music annoys him, so Olivia no longer listens to her music.

**Accommodation.** Olivia’s pattern of engagement in several areas of occupations such as IADLs (health management, religious observation, and meal preparation), rest and sleep, leisure, social participation (family and friends), and work were affected by Joey’s CVA. Prior to Joey’s injury, Olivia spent the time that Joey spent in his own occupations to engage in several activities. Since the injury, her time away from Joey has been reduced and she had to make several changes to her previous engagements in occupations.

**Social Participation.** Prior to his injury, Joey was a hunter, and would take trips that lasted weekends at a time. While he was gone Olivia would go shopping with her girlfriends, to movies, and have overnight stays at a cabin. She said that “[my] girlfriends and I, we’re shoppers” and could spend the day going “antiquing.” In addition, when Joey was at sporting events, Olivia would see her grandchildren taking “every chance [she]...had” to see them when he wasn’t around.

After Joey’s CVA, her outings with her friends became “few and far between,” and we would “just do lunch, and that takes couple of hours.”
Moments with her grandchildren are now “probably twice a month…on weekends….I’ll go up to their place and spend an hour or two.” Olivia can no longer have an entire day to interact and “go over the top” with her grandchildren anymore since Joey needs supervision in many tasks.

In addition to Joey’s need for supervision limiting her ability to spend time with her family, Olivia did not feel the same level of connection with her children as she had prior to Joey’s injury, which created a sense of abandonment for her. As a result, her time with her children and their families has changed too. Olivia expressed frustration that the children did not volunteer to relieve her and take care of Joey. She said that “the kids are all too busy to help: nobody seems to really be interested or offers. And that’s been very devastating.” Olivia went on to say that “nobody ever calls and says, ‘Gee, Olivia, how’s your day going? Could you use some time off?’…Nothing…overall I think everybody’s forgotten.” This resulted in resentment, and Olivia stated that if the kids were not going to call and offer help, then she would not call them either.

**IADL: Health management, meal preparation.** Olivia has stopped enjoying cooking and is not eating as well as she was prior to Joey’s injury. Before the injury she stated “eating…was a pleasure,” and that she “would bake cakes…[and] cookies a lot,” and now she feels like “I don’t care what I make.” When asked about eating after Joey’s injury she said “not much time. That really is pathetic.” Her patterns of eating and cooking have changed significantly and she had been recently diagnosed with an ulcer.
**IADL: Religious observation.** Olivia and Joey continue to attend church, but did not participate in the same manner. They used to greet people together, but Joey had stopped due to feeling uncomfortable with the reactions people would give when they would “say hello to him, and he’ll say, ‘Thank you’…so…he just hangs out.” Olivia continues to greet people without him.

**Rest and Sleep.** When asked how she was sleeping prior to Joey’s CVA she stated that “he had terrible insomnia….Oh, it would drive me nuts…it was awful.” When Olivia described sleeping post-injury she mentioned that the insomnia seemed to have gone and that “he’s able to sleep, and that’s wonderful,” inferring that her nights of sleep are now uninterrupted.

**Work.** Olivia was employed in a full-time job prior to Joey’s injury. She said that “I loved my job….I was the regional administrative assistant for a company, and…managed the six local offices.” At the time of the interview, she had a part-time job at the school district. She reported enjoying her job a great deal.

Olivia stated that the four hours away at work was a “kind of a break for me…when the opportunity came…it just really was a blessing…it’s just good to feel productive again, and…get my mind off…the same [daily] routine.” Olivia was facing another change in her work pattern at the time of the study. She stated that she was considering giving up her work because she had “noticed that his health is declining….So…that really has to be a priority right now.”
**Leisure: Travel.** When asked if they traveled prior to the injury she said “as often as we could…to the cabin, sometimes two and three times a month…to Oregon…and Eastern Washington to visit family…to Mexico every year…on a couple of cruises. Yeah, we loved to go.”

Travel had changed after Joey’s stroke, however. At the time of the study, Olivia reported that if they went to the cabin she had to spend time to get everything ready. She said that “it’s just a lot of preparation…getting the car packed up…getting up there, and getting everything…de-winterized.” In addition, if Joey saw the cabin “really un-kept…[it] really upsets him.” As a result, they had decided to sell the cabin because they had begun to “almost argue about having to go…because…I have to take care of it, and we’re not in an area where you can get somebody to help.”

When asked what she would choose if she could have more time for one leisure activity, Olivia said “travel, travel, travel…slow me down more. Just time to stop and smell the roses, you know?”

**Leisure: Gym, and reading.** Olivia stated that before Joey’s stroke, “reading…[was] relaxing, and also working out [at] the gym, it’s what I love to do, and it really eases the stress for me to work out.” Since the injury, she has managed to go to the gym “four or five days a week” but Joey sometimes went with her.

Reading time also increased for Olivia post-injury. Pre-injury she stated that she “didn’t have a lot of time…[but] would read [when]– we’d go to the
cabin….He would read the Reader’s Digest occasionally.” After the injury she started reading more because Joey began to “sit and read – read the newspaper and read a book.”

**Initiation.**

**Leisure.** Prior to Joey’s CVA, Olivia was always on a “dead run” going from her job to the gym then home to prepare the meals. She said that “I’m not a T.V. person…I’m one of these people that can’t sit still…the minute I sit down I fall asleep.” However, after Joey’s injury Olivia started to sit by Joey and eat with him and watch his television program.

**ADL: Bathing.** Olivia didn’t take baths before, and now she takes one on most nights. She says that before the injury she was busy from the start of her day to the end and went straight to bed at night without having time to relax. After Joey’s stroke, Olivia began to take an occasional nightly bath and reported that was relaxing for her.

**Rest and sleep.** Before the injury, Olivia’s and Joey’s nightly routine consisted of them working “together…[to] close up the house for the evening…then we’ve have time for us.” Now she sometimes doesn’t make it up to bed and said that “I’m just so exhausted, sometimes I even fall asleep on the sofa….So, I hope I don’t wear out.” She had a set routine before Joey’s stroke that was balanced and enabled her to make it to bed every night. After Joey’s injury, she had more responsibilities and reported more fatigue from the day’s activities.
Discussion

Partners of survivors may experience alterations in their patterns of engagement in occupations post-injury. The aim of this study was to examine the pre- and post-injury patterns of occupational engagement for a partner of someone with ABI six years post-injury. Effects of her partner’s injury on the participant of this study resulted in her role as wife being redefined and the cessation, accommodation, and initiation of occupations. Further discussion of the results are framed using the Occupational Adaptation (OA) model developed by Janette K. Schkade and Sally Schultz.

The OA model, described in *Occupational Adaptation: Toward a Holistic Approach for Contemporary Practice, Part 1* (Schkade & Shultz, 1992), considers how people adapt their behavior so that they remain functional. The model helps inform occupational therapy practitioners by focusing on improving a person’s ability to adapt in order to meet occupational demands. The OA model has three components: person, occupational environment, and the interaction “of the two as they come together in occupation” (Schkade & Schultz, 1992, p. 831). These three components each contribute to mastery of occupation. The person is driven by an internal motivator towards mastery but must work within the context of the occupational environment. Ultimately, when faced with an occupational challenge, an occupational response is generated, influenced by the person, the occupational environment, and the way in which the two interact. In the case of Olivia, the person component in the OA would be her desire to master the role of
wife, the occupational environment component (external) would be the demands placed on her for the role of primary caregiver in supporting Joey, and a successful occupational response would result in the maintenance of her healthy sense-of-self.

The occupational environment she must function within requires her to assist Joey with his daily activities and medical needs. The demand on Olivia by the occupational environment has impacted her ability to engage in occupations, thus hindering her ability to maintain her sense-of-self. With reduced time to herself, she has lost the “peer-based reciprocal relationships” that she previously enjoyed with her friends (Wood et al., 2005, p. 845). Without her family volunteering to assist with Joey, Olivia must strive to meet the demand for mastery without the “primary source of support, socialization and assistance” the family may provide (Burridge et al., 2007, p. 96). Lack of respite from being on-call 24/7 to provide care for Joey renders her with limited personal time (Poulin et al., 2010). The lack of support she receives also causes her to feel abandoned and decreases the time she has for herself and with friends and family.

Furthermore, the demands from the occupational environment and the press to master her occupational demands, has challenged her ability to adapt and has generated feelings in Olivia contradictory to a healthy sense-of-self. The dynamics in her marriage to Joey that she confronts are the loss of expressed affection from Joey (Peter et al., 1992), his aphasia interfering with their social
participation together (Peters et al., 1990, and Wood et al., 2005), and lack of respite from providing daily assistance for Joey (Poulin et al., 2010). All of this negatively impacts Olivia’s ability to establish a healthy sense-of-self and has led to a maladaptive occupational response. The routine of providing care and the knowledge that Joey’s condition is getting worse presses Olivia to make occupational adaptations. Her faith in God provides a source of comfort for her, but without the support she needs for respite, Olivia is limited in her ability to successfully adapt her occupational patterns in order to establish a healthy sense-of-self. Additional factors also affect Olivia’s ability to adapt to the post-injury relationship.

Each theme had broader implications affecting Olivia’s ability to generate an effective occupational response. The activities she ceased provided her opportunities to experience spontaneity and excitement. By incorporating the role of primary caregiver into her role as wife, she experienced a reduction of time to engage in several occupations. Furthermore, the activities she initiated were more passive and home bound. The cumulative effects of these implications resulted in Olivia losing opportunities to be removed from stressors and generate ideas passively (referred to as the secondary level of adaptation energy of the OA model) (Schultz, 2009). Olivia’s current occupational response has left her feeling caged, exhausted, abandoned, frustrated, removed from family and friends.
However, there were several positive outcomes indicated in the interview. For instance, Olivia and Joey were fortunate that their retirement plans were already set before the injury, Olivia’s sleep is now uninterrupted, and Olivia never spoke of financial concerns. Furthermore, current studies highlight other positive indicators that support Olivia in mastering the press of the integration of the person and occupational environment in order to stay with Joey and establish a healthy sense-of-self.

Olivia and Joey are both older adults and were married for 17 years prior to the injury increasing their chances of remaining together by three times over their younger peers (Kreutzer el al. 2007). Joey’s functional impairments were lack of balance and forgetting steps, not the hemiparesis that is present in most CVA cases. Joey’s ability to use one side of his body enables him to function more effectively than his peers with hemiparesis. According to Peters et al. (1992), the level of function that Joey presents increases the likelihood that Olivia will successfully adapt to the changes in the partnership dynamics.

**Implications for Occupational Therapy**

Occupational therapists (OTs) provide direct treatment to ABI survivors and provide suggestions and guidance to their partners. The current literature on the topic of effects of ABI on the partner’s ability to engage in occupations is limited. This study provides insight into how a partner’s ability to engage in occupations is affected by the sequelae of the ABI to her partner. With information from this study, OTs can provide specific examples to the client’s
partner of what they may experience in terms of future occupational engagement.

In order to provide optimal care to the client’s and promote their health, attention must also be directed to maintaining the support system currently in place. Suggestions from Burridge et al. (2007), Eriksson et al. (2005), and Peters et al. (1990) are to include the survivor’s partner in the treatment sessions; however, current reimbursement systems do not pay for providing direct services to the client’s partner or primary care provider (Braun & Wake, 1988). To facilitate the client’s treatment and ensure optimal results, further advocating for reimbursement to cover costs for providing direct care to the client’s support system is necessary.

Limitations

Limitations to this study are small sample size and that the survivor did not present with the typical stroke symptoms (i.e., hemiparesis). Another limitation was that the coding was conducted solely by the researcher, thus increasing the chances for a biased interpretation. Moreover, having only one person generate the codes reduces the reliability of emerging themes (Kielhofner, 2006).

Future Research

Further research, both quantitative and qualitative, is needed to explore the changes in patterns of occupations of the survivor’s partner. Specifically, participants should include partners from same sex relationships and male
partners of survivors. In addition, exploration of the changes in expressed emotional and physical affection would be informative.

In addition, a guide on “how to address the progression of the ABI and the need for respite care to family and friends,” would benefit the partners of survivors without taking much time away from treating the client when asking for support from family and friends.

**Conclusions**

The impact of Joey’s CVA significantly changed the dynamic of his and Olivia’s marriage. Adjustments had to be made by Olivia to maintain her role as Joey’s wife. She ceased or initiated several activities while adjusting many more, to be able to meet the demands placed on her to remain Joey’s wife and primary care provider. The increase in the demands from the occupational environment, to be Joey’s wife, had challenged Olivia’s ability to adapt and maintain a healthy sense-of-self. She had experienced decreased time with friends, work, activities she and Joey did together, time at the cabin, and time with her grandchildren. She stopped several activities like baseball (losing an exciting and spontaneous activity), and hiking (losing an outdoor activity she and Joey did together), and started watching television with Joey, and occasionally falling asleep on the couch, instead. She had become more isolated from her friends and family but also felt blessed to have her husband. Her desire to master the role of Joey’s wife was strong and many factors, including the length of the relationship pre-injury,
Joey’s level of function, and being older adults indicate a positive prognosis towards her attempts of maintaining the marriage.

References


Marriage after brain injury: Review, analysis, and research 


*NeuroRehabilitation, 22*, 53–59.


Appendix A

**Demographic Information:**

Age: _______________________________

Sex: _______________________________

Date of Partner’s Injury: _______________________________

Degree of Partner’s Injury: ________________________________________________________________

Cause of Partner’s Injury: ________________________________________________________________

Education Level of Partner with Injury: (circle one)

High School / Some College / 2 year Degree / 4 year degree / Post-graduate studies

Education Level of Partner without Injury: (circle one)

High School / Some College / 2 year Degree / 4 year degree / Post-graduate studies

Length of Relationship Pre-injury: _______________________________

Length of Relationship Post-injury: _______________________________

Additional diagnosis: _________________________________________________________________
Appendix B

Interview Guide

Questions are grouped in a parallel scheme to spur reflection and maintain focus on the topic of either pre-injury or post-injury.

Pre-Injury:
Describe how you spent your time during a typical day before your partner’s injury.

If asked for clarification or for examples: Describe your self-care routines.

Tell me about the activities that you were involved in before your partner’s injury.

If asked for clarification or for examples: Describe how you spend your time with friends, family, or acquaintances. Describe how you spent your time in leisure pursuits.

Can you tell me about activities that you did with your partner before the injury.

Why were those activities important to you?

Did you work then? Can you describe to me how your work life was like?

Post Injury:
Describe to me how you spend a typical day now.

If asked for clarification or for examples: Describe your self-care routines.

Tell me about the activities that you have been involved in after the injury.
If asked for clarification or for examples: Describe how you spend your time with friends, family, or acquaintances. Describe how you spend your time in leisure pursuits.

Tell me about activities that you do with your partner now.

Why are these activities important to you?

Do you work now? Can you describe to me how your work life is now?