AN INVESTIGATION OF CHANGE IN THE LIVES OF SPOUSES OF AMNESTIC INDIVIDUALS

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy Graduate Department of Applied Psychology and Human Development Ontario Institute for Studies in Education University of Toronto

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The purpose of the present study was to explore the ways that spouses of persons with ABI experience a process of change in roles, routine, and overall lifestyle and the subsequent implications for their support needs. The present study used a qualitative narrative inquiry methodology to examine the process of the experiences of this population of spouses. In-depth semi-structured interviews were conducted with 15 spouses, each of whom was engaged in a heterosexual relationship. There were 10 female and five male participants whose ages ranged from 40 to 61. Twelve of the participants were formally married, and three were in a common law relationship. In the interviews, the participants were asked about the changes in their lives after the onset of their spouses’ brain injuries. The data analysis was informed by narrative inquiry with attention paid to the structure of the participants’ stories. A three phase trajectory of caregiving emerged from the analysis which provided details regarding the process of change in the spousal caregiving role and how various role transitions within this role were intertwined with stressors and other feelings. The research highlighted three phases of caregiving including an Embryonic, Immersed and Modified Caregiver phase. The findings were theoretically important for identifying: how these spouses situate themselves within role transitions; coping strategies; various support needs; and future directions for research in this area.
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INTRODUCTION

Due to the technological advances in medicine, survival from neurological trauma has become increasingly common (Rosenthal, Griffith, Bond & Miller, 1983). In Ontario, there are approximately 500,000 neurotrauma (acquired brain injury & spinal cord) injuries per year resulting in costs to the province of 2 to 3 billion dollars annually (Ontario Neurotrauma Foundation, ONF 2011); suggesting that the total number of injuries in Canada and the total cost to the federal government would be significantly more. Projected costs to individual families impacted by acquired brain injury are more difficult to estimate but would include considering: lost income of the brain injured individual (and possibly the caregiver spouse); rehabilitation costs; medication costs; other treatment costs (i.e. emotional support); travel costs; home renovation costs; attendant care; childcare and more. Of note, there is no price for the emotional and psychological costs (Hutchinson, 2010). Acquired brain injury (ABI) results from external trauma (i.e. car accident), termed traumatic brain injury (TBI), or from a medical problem (i.e. aneurysm, encephalitis), termed non-traumatic brain injury (non-TBI). There are more people with ABI than the total combination of people with AIDS, breast cancer, spinal cord injuries and multiple sclerosis. Furthermore, in Ontario, non-TBI is more common than TBI and non-TBI individuals represent the highest need for medical services when compared to TBI individuals (Richards, 2009).

Traumatic and non-traumatic brain injuries are classified as mild, moderate, or severe in nature. These classifications are made based on the changes in the level of consciousness of the individual after the injury along with the extent of retrograde and anterograde amnesia. The level of consciousness is usually rated at certain periods in time by medical personal using the Glasgow Coma Scale which provides a score ranging from 3 to 15 (Woo &
The type of brain injuries that were relevant to this study were in the moderate to severe range. For moderate injuries the GCS score ranges between 9 and 12 and for severe brain injuries the GCS score would be less than 9 at the time of the injury (Woo & Nesathuri, 2000). Thus, a lower score denotes a lower level of consciousness. Moderate to severe brain injuries can result in a number of emotional, cognitive and physical deficits. Cognitive deficits that have been identified for people living with moderate to severe brain injuries typically have included significant reductions or impairments in the areas of attention, memory, processing speed and executive functions with maintained functions in language and visuospatial skills (Zgaljardic & Temple, 2010). Moderate to severe brain injury can also result in emotion regulation problems resulting in difficulty controlling emotions in the moment or in the general regulation of affect resulting in mood disorders such as depression (Kreutzer, Marwitz, Seel, & Serio, 1996; Povlishock & Katz, 2005). Woo and Nesathuri (2000) identified that these brain injuries may have co-morbid physical changes such as fractures, soft tissue injury, changes in mobility and paralysis. Colantonio et al. (2004) found that individuals with these injuries experienced difficulty carrying out complex tasks such as managing money or navigating trips outside the home such as shopping. Svoboda and Richards (2009) suggest that moderate to severe memory impairments resulting from a moderate to severe non-traumatic brain injury most commonly can cause an individual to be inconsistent or unable to create new memories. Being unable to form new memories is referred to as “severe memory impairment or amnesia” (p. 629), and this phenomenon can cause individuals to become stuck in the present because they cannot make future plans or engage in the activities necessary to complete future plans due their inability to recall recent events and to follow through with tasks to completion. With regard
to prognosis, Povlishock and Katz (2005) have identified that recovery from severe ABI is the most lengthy process of neurological recovery and it involves a series of stages such as recovering from a coma in several days to weeks, then several weeks to several months of recovering from post traumatic confusion and amnesia, and then several months to years of recovering various cognitive and social functions. Over the years, the literature has diverged about the prognosis for recovery from severe TBI and Povlishock and Katz (2005) provide up to date information suggesting that five years is the longest documented recovery period for cognitive and social functions, and it is emphasized that brain structures and cells cannot be regenerated. Thus, the initial recovery is usually an upward trajectory that tapers off due to permanent damage to brain cells and this is different than that of a neurodegenerative illness which causes damage and subsequent cognitive decline over time. Despite the upward trajectory of recovery in moderate to severe ABI, many individuals with this type of severity in brain injury do not return to work (Colantonio et al., 2004).

Unfortunately the cognitive impairments that often result from ABI require long-term health care considerations (Svoboda & Richards, 2009), particularly in the community. When a person returns home from hospital after suffering neurological trauma, spouses and family members are not only left to provide care but also endure enormous life adjustments and burden (Jackson, Turner-Stokes, Murray, Leese & McPherson, 2009; Holm, Schonberger, Poulsen, & Caetano, 2009). Although there are community supports available to families in many cities, a study of persons with ABI and their families conducted by the Ontario Brain Injury Association (2007) found that many families were not accessing support group services, home support services; or nursing services. Thus, it appears that many services are not utilized by ABI patients and their families in Ontario, and it was determined that the
reasons why various families do not access services remain unclear. Because ABI requires many healthcare services and supports after the acute phase in hospital, it should be considered to be a chronic disorder (ONF, 2011). Long term community support of families from a rehabilitation perspective has been identified as a priority (Boschen, Garago, Gan, Gerber, & Brandys, 2007).

The reality of many health care systems unfortunately involves limited access to service for post acute brain-injured individuals and even fewer services for spouses of those individuals. Furthermore, many families are likely to be unaware of all of the services available to them. Hence, exploring the needs for these individuals may further inform our healthcare system about the most pertinent ways to help these families cope. Thus, this study aimed to examine the experiences of spouses of individuals with ABI in order to adequately understand their unique experiences within their families and out in the community; and to identify their overall needs. A qualitative narrative methodology was used to investigate these issues.

The present manuscript begins with a literature review which summarizes past research in this area and future needs for research identified in that body of work. Further, an examination of the phenomenon of spousal caregiving and its relationship to theories related to stress and role transitions was conducted. This is followed by a description of the methodology used to collect and analyze the data. The results of the study were divided into six sections that summarize the impact to the brain injured spouses and subsequent experiences of the well spouses, with three core sections emerging as a summary of a caregiving trajectory. The discussion summarizes the findings in the results and compares these findings with related literature that in turn exemplifies a process for caregiving and
identifies various coping strategies used by these spouses. The strengths, limitations, implications for future research and potential theoretical clinical applications of the findings are also summarized in the conclusion.
CHAPTER ONE
LITERATURE REVIEW

Caregivers of Individuals with an Acquired Brain Injury

The literature in the area of family members of persons of ABI is often divided into investigations pertaining to spouses, parents, grandparents, siblings, and children. Florian and Katz (1991) suggest that family members such as parents and children, and spouses of individuals with ABI should not only be viewed as caregivers but also as a target treatment population. In fact, Gan, Campbell, Gemeinhardt, and McFadden (2006) reported that the family members are more likely to become distraught by the injury than the actual brain injured individual because the brain injured person often lacks insight into the way things have changed. Gan, Garago, Brandys, Gerber, and Boschen (2010) suggest that the cognitive changes in the individual may not be completely apparent in the immediate acute phase of recovery and thus the ramifications for returning home are likely not completely understood; leaving families underprepared for the homecoming of their family members. This research examined the needs of families impacted by ABI through the analysis of caregiver perspectives in conjunction with the experiences of program representatives and researchers. This research questioned whether lack of supports results from barriers to accessing service, a lack of breadth of service or insufficient resources. Subsequently, it was found that having enough support for the person with ABI was imperative for the coping of the caregiver. Overall recommendations included firstly, family systems based support (including access to services for all family members that is life-long, continuous and timely); and secondly, support systems located where professionals work collaboratively to provide ABI specific, proactive, responsive, continuous, and multi-component services.
A review of the research regarding spouses of individuals with ABI revealed a limited body of literature because the area of focus is often on the other types of family members (i.e. parents of a child with ABI). Nonetheless, it has been identified that spouses may have a distinctly different experience than that of a parent, grandparent, sibling, or child of a brain injured individual (Florian & Katz, 1991).

The Experiences of Spouses

Anderson et al. (2009) explored the differences between the experiences of parents and spouses of individuals with TBI and found that spouses of individuals with impairments in cognition and behaviour endured significantly more difficulty in family functioning but experienced less psychological distress than parents. These differences in experiences of the different types of caregivers of persons with ABI suggest that further understanding of spouses’ experiences would enable healthcare professionals to better target their unique treatment needs. Thus, it is appropriate to surmise that enhancing the coping of these spousal caregivers would in turn enhance the lives of the individuals with ABI.

Other populations of spousal caregivers. Although there is considerable information available about caring for persons with dementias; the issues relevant to spouses/caregivers of individuals with ABI is less expansive. Many realms of experiences between these two populations of caregivers however, may be compared and contrasted in order to broaden theoretical perspectives. For example Jackson et al. (2009) point out that caregivers for people with dementia are typically older and thus face different life challenges. Further they identified that it is likely that people who have non-degenerative neurological events are more likely to be younger and still in the workforce resulting in a significant impact on their family income. Spousal caregivers for persons with dementia are more likely
to be retired and likely have different financial circumstances. Individuals with ABI may be in their child rearing years and have young children, leaving spouses to manage the care of the household and young children, in addition to the spouse with ABI. In contrast, caregivers of those with dementia more commonly have adult aged children who may offer additional support. Furthermore, marriages may be less established and less stable in younger couples thus leaving those couples to be more vulnerable when impacted by the life challenges of living with a head injury. Overall, as in the dementia caregiving literature, the current ABI/TBI literature suggests that spouses of persons with ABI experience significant stress and burden associated with the enormous changes in their lives causing them to require attention and unique support services within our health care system (Gan et al., 2006; Holm et al., 2009; Jackson et al., 2009). Jackson et al. (2009) compared the caregiving experiences of spouse of people with dementias and ABI and they found that the ABI caregivers did experience greater feelings of burden and this was related to the fact that they were more likely to reside with the care receiver and thus likely to spend longer periods of time caregiving.

Research in the area of caregiving for people with dementias provides a wealth of valuable information and important theoretical comparisons for the role of caregiving for an individual with a neurological condition. Even though there are many differences that have been theorized and established between the experiences of ABI and dementia caregivers, there are also similarities. Jackson et al. (2009) found that both of these populations of caregivers endured outcomes such as increased burden, compromised mental health, and reduced quality of life. Furthermore, it was identified that the behavioural difficulties associated with neurological changes were highly predictive of poor coping and subsequent
burden in these two caregiving populations. Research in the area of adult children caring for parents with dementias raises considerations for similar experiences such as navigating work and caregiving and, feelings of responsibility related to engaging in the caregiver role. Wang, Shyu, Chen, and Wang (2010) found that navigating work roles in addition to dementia caregiving roles lead to role strain and subsequent problems with depression. Navigating a number of demanding roles such as caregiving, parenting and work is an issue that would also be important to investigate in spouses of individuals with ABI because they are generally a generation of caregivers that are of employment age.

Information can be gleaned from the *dementia* caregiving literature regarding role transitions and psychological frameworks for caregiving that may be comparable to the experiences of spousal caregivers for individuals with ABI. Because both conditions involve changes in cognition it is likely that both groups of caregivers would endure many changes in roles within the home. Ducharme et al. (2009) utilized the Meleis et al.’s (2000) role transition model to inform a caregiver education intervention program in order to address the temporal and changing nature of the caregiving role. The findings had important implications for the timing of educational interventions that would assist with successful role transitions. The skills identified to navigate successful role transitions included understanding the illness, developing problem solving skills, developing communication skills, seeking support, and finding meaning in the caregiving role. These findings may also be helpful if applied in some manner to investigations of spousal caregivers for individuals with ABI who would need to address similar issues. Many researchers such as Zarit and Whitlach (1992) developed theoretical frameworks for caregiving transitions and phases and it has been suggested that spousal caregivers for people with dementias go through a process of change and transition.
This concept can likely be applied in some way to the experiences of spousal caregivers of individuals with ABI, however, the nature of the stages or phases may be different. For example, many models or frameworks for caregiving in dementias involve a series of stages and the series often conclude with an end stage such as Lindgren’s (1993; as cited in Donorfio & Kellet, 2006) “encounter, enduring, and exit” series of the caregiver career stages, or Skaff, Pearlin and Mullan’s (1996) caregiving transition end stage of “bereavement”. Donorfio and Kellet (2006) completed a systematic review of numerous dementia and elderly caregiving framework studies and identified several spousal focused studies that investigated caregiving stages, transitions, and roles. A present review of the literature revealed that there are significantly fewer studies published in the area of spousal caregiving and ABI. The dearth of studies regarding theoretical frameworks and processes of change for ABI spousal caregivers suggests that research is needed in this area and it is likely that the model of caregiving would take on a different sequential trajectory than that of dementia specific caregiving models.

**Issues that impact spouses of individuals with ABI.** There are many areas of daily functioning that can be affected when one’s spouse suffers an ABI. There is the obvious initial grief and loss in response to the brain injured spouse’s changes in cognitive and physical functioning. However, the well spouse often does not have the time to mourn these losses because they have initiated caregiving while trying to maintain the status quo of the household for children or other dependents. Thus, these potentially overwhelmed spouses may be at risk for developing stress, depression, anxiety, and other health problems (Blonder, Langer, Pettigrew, & Garity, 2007; Larson, Franzen-Dahlin, Billing, Murray, & Wredling; 2005). These spouses have been found to encounter more familial responsibility, financial
responsibility, and household responsibility (Florian & Katz, 1991; Gan et al., 2006). There may be changes in employment, relationships, and changes in their social life (Buschenfeld, Morris & Lockwood, 2009; Larson et al., 2005). Spouses take on the juggling of family needs in conjunction with new spouse needs such as dealing with problematic behaviours, attending appointments, and providing care with inadequate support. Essentially they must add this work on to their already demanding life of working and rearing children; and manage these roles in conjunction with any of their own potential difficulties with depression and anxiety (Anderson, Parmenter, & Mok, 2002; Gillen, Tennen, Affleck, & Steinpreis, 1998). Other changes that these spouses might encounter are qualitative differences and reductions in sexual intimacy (Arenhall, Kristofferzon, Fridlund, & Nilsson, 2010; Florian & Katz, 1991). In fact, changes in sexual intimacy for these couples were first identified in Rosenbaum and Najenson in 1976 (as cited in Florian & Katz, 1991). Many of these changes represent changes in roles for these spouses, and navigating those transitions can be very difficult.

Spouses of individuals with an ABI have been found to encounter a number of issues particularly at the time of returning home from acute care. Anderson, Parmenter and Mok (2002) have identified that spouses primarily carry out the burden of care for individuals with ABI once the brain injured individual goes home. They investigated the relationship between chronic stressors and psychological distress for these spouses and found that family functioning mediated the relationship between chronic stressors and the experience of distress. The most significant stressor noted was behavioural problems associated with reduced cognitive functioning. Thus, the spouses appeared to experience increased distress based on appraisals of reduced family functioning. The lack of supports in the community for
both the well and unwell spouses have been linked to poor coping and burden. Buschenfeld et al. (2009) identified that spouses caring for stroke survivors had difficulty accessing services for their partners that were age appropriate. Furthermore, Eldred and Sykes (2008) identified a need for improving the effectiveness of support services and interventions for the well spouses themselves in order to enhance coping. Chwalisz (1996) theorized that perceiving the caregiver role as stressful likely leads to feelings of depression and anxiety. Chronister and Chan (2006) identified an important connection between social supports and caregivers’ experiences of stress. In fact “stress process models” have been used to investigate the experience of ABI spousal caregivers and this suggests that emotional health, coping, and burden are important issues to consider for this population. Overall, it appears that spouses of individuals who have experienced an ABI are required to take on many new roles in the context of caregiving and these roles are often taken on without psycho-education, knowledge dissemination, or formal supports. The lack of support along with chronic stressors has been identified as resulting in experiences of stress, poor coping and subsequent burden for these spousal caregivers; however the process and nature of these experiences appears to require further investigation.

**The Process of Role Transitions**

Spouses of persons with ABI experience many changes in their relationships, everyday life, and lifestyle. Furthermore, they most often are required to take on a caregiving role for their brain injured spouse. A small portion of the literature pertaining to these well spouses has identified the phenomenon of role transitions, and how these spouses encounter role transitions in the process of adjusting to their spouses’ brain injuries (Chronister & Chan, 2006; Hammond, Davis, Whiteside, Phil brick, & Hirsch, 2011; Leathem, Heath, &
Woolley, 1996). Upon reviewing this literature, it became apparent that very few findings regarding role transitions were qualitatively described and rather were mostly quantified in nature either being separated out as a moderating or outcome variable (Chronister & Chan, 2006). Information regarding role transition phenomena may be more helpful and informative if it includes a more in-depth understanding of what type of role transitions take place, how these role transitions happen, and when spouses can expect to experience role transitions. Finally, questions arise regarding the impacts of role transitions on the dynamic of households and the mental and physical well-being of the well spouses. A recent qualitative study has investigated the dynamics of TBI couples and how marital adjustment plays a role in their ability to stay together due to the difficulties that develop (Hammond et al., 2011). Changes in family dynamics were found to be related to difficulties in navigating role transitions, however, the types of role transitions were not the focus of the examination of this data. Thus for the present study, pursuing an expanded examination of the context of role transitions for these marital dyads was determined to be a necessary next step of investigations for this population. Hence, the present investigation was developed to provide an in-depth analysis of the ways role transitions were experienced by the spouses. Spouses who are thrown into a caregiving role for a partner likely experience many role transitions regardless of the type of illness or injury. For example, the move from the acute care setting to home has been identified as a significant transition period for the family of an individual with TBI because it often results in challenges for coping and managing stress (Gan et al., 2010; Parmesan & Arco, 2007). This research identified various areas that need to be addressed during this period such as access to psychological support, family support, discharge planning preparation, ensuring access to community support services such as case
management; and addressing engagement in meaningful activities for the brain injured individual (Turner et al., 2007).

Role transitions within the marital dyad where one person has an ABI can involve new parenting roles, new administrative roles within the home (i.e. finances, different chores), and possibly a new dynamic for the couple where the caregiver takes on a parenting type role for their spouse. These types of role transitions can have a significant impact on the mood and mental health of these spouses. Meleis et al. (2000) theorized that elements of a successful role transition include the development of new skills and knowledge, perceived social support, and perceived self-efficacy in stressful situations. In related literature, Ducharme et al. (2009) found that timing therapeutic interventions for caregivers of persons with dementias to the care trajectory (in this case at the time of diagnosis) were most effective for guiding role transitions. It is possible that this type of approach may also be suitable for spousal caregivers of brain injured individuals. Ducharme, Levesque, Lachance, Kergoat, and Coulombe (2011) also identified that the key to successful role transitions for caregivers of individuals with dementias included feeling prepared, being provided adequate social support, and having access to knowledge about formal services. These factors have been identified in the ABI caregiver literature but not in relation to roles. For example, Florian and Katz (1991) recommend that caregivers of persons with ABI received guidance regarding information and emotional counselling support in order to enhance coping and adjustment. Also, Gan et al. (2010) recommended that access to information and support services for family caregivers should be improved and implemented as long term. Thus, the factors have been identified however the relationship between these factors and role transitions needs further exploration in the ABI literature.
There seem to be natural timelines for role changes within families such as the changes from wife to mother to grandmother (Burton, 1996). Consequently, untimely role changes are theorized to result in significant stress for family members. Caring for an individual with ABI can be considered to be an “untimely” role change, as it is likely quite unexpected given the life stage of the couple (i.e. not aging). Thus, the untimely role transitions for these spouses may significantly threaten their perception of their ability to handle these changes. It is important to consider the psychological impact of taking on a caregiver role for a spouse. Often the role of caregiver for a spouse is new to an individual, and hence there are many unknowns regarding the caregiver role (Chwalisz, 1992; Donorfio & Kellet, 2006). Facing unknown challenges can be very stressful to an individual; however, the individual’s perception of the situation may most greatly influence the amount of stress experienced.

A Model for the Structure of Role Transitions

Meleis et al. (2000) developed a role transition model that describes a transition as a period of confusing and unclear changes from one role to another that leaves the individual to perceive the role transition as ambiguous. They developed a framework of role transitions that asserts that the process of a role transition is complex and involves five interrelated properties: awareness, engagement, change and difference, time span, and critical points and events (p.18). These five properties are what constitute the complex process.

Awareness. In Meleis et al.’s (2000) framework for role transitions it was theorized that an individual will likely come to state of awareness about their role transition. They suggested that individuals do not necessarily have to be aware that their role is changing but
awareness does help them make the change. A person’s level of awareness is considered to be aligned with their prior knowledge of others in similar situations.

**Engagement.** For a role transition, the person’s level of awareness was theorized to directly impact their level of or ability to engage with their transition. Meleis et al. (2000) define engagement as an individual’s attempts to modify or interact with their transition experience through various strategies such as: modifying behaviours or activities proactively, sourcing out information, learning from role models, and attempting to be prepared for situations. The person’s amount of active engagement is thought to be correlated with their level of involvement in the process of their transition. The framework suggests that those going through a transition and are more aware of situational changes to their environment, physical status, psychological status, or social status will be more engaged with their transition process.

**Change and difference.** Change is an inherent part of the transition process. Meleis et al. (2000) theorized that “transitions are both the result of change and result in change” (p. 19). Meleis et al. (2000) suggest that in order to understand a transition process, the meaning of the underlying changes must be examined. Change can be associated with shifts in relationships, routines, ways of thinking, and personal identities.

**Time span.** Transitions occur over periods of time and Meleis et al. (2000) purport that it is difficult to determine exact timelines for role transitions including the beginning and end points for any type of transition. They recommend that transition outcomes may need to be reevaluated over time as unknown factors may cause the re-experiencing or an evolvement of a role transition. Overall, they suggest that it would be difficult to establish deadlines or parameters of that nature for role transitions.
**Critical points and events.** The initiation of a role transition often coincides with a critical event in the lives of those involved. In the case of this examination the onset of the acquired brain injury would be an example of a critical event. However, not all role transitions begin with a noticeable incident (Meleis et al., 2000). In addition, various critical points may occur during the process of a role transition that may change the trajectory of that transition. For example, gaining a new skill, developing a new routine, or developing a new sense of awareness about one’s situation is an example of critical points that occur during a role transition. Meleis et al. (2000) suggested that role transitions associated with caregiving may be divided into critical periods where people shift through phases associated with the types of caregiving tasks that are required at various points in time.

**A framework for role transition conditions, process, and outcomes.** In addition to the five properties of role transitions, Meleis et al. (2000) theorized that there are many other factors, named “transition conditions” (p. 20) that facilitate or inhibit a well adjusted transition. They suggest that all aspects of a person’s environment such as community norms, societal norms and personal ideologies contribute to the nature of the role transition. The “personal transition conditions” (p. 20) that impact role transitions in a positive or negative way are: meanings, cultural beliefs and attitudes, socioeconomic status, and preparation and knowledge. Thus, personal meanings and beliefs about one’s situation may inhibit or facilitate their role transition process. Having knowledge and being prepared would be considered facilitators of the role transition process, while the opposite would be considered an inhibitor. The “community transition conditions” (p. 22) include community supports, information, role models, and resources. Therefore, the more support information and resources available, the “healthier” the process of the role transition. “Societal transition
conditions” (p. 22) that could be considered include stereotypes and the potential for marginalization or equity considerations of groups. These more global aspects of society reflect obstacles that are significantly difficult to overcome as these issues are not directly related to the role transition itself but are a reflection of a person’s circumstance. Meleis et al. (2000) suggest that the types of personal, community, and societal transition conditions experienced by individuals are important to consider as individuals experiencing similar role transitions (i.e. such as caregiving) may experience significantly different transition conditions.

Meleis et al. (2000) identified important “process” (p. 23) and “outcome” (p. 24) indicators for role transitions. The indicators of the *process* included themes of feeling connected, interacting, location and being “situated” (p. 23), and developing confidence and coping. Feeling connected to a community which includes not only connecting with others having a similar experience but also continuing a connection with community resources such as medical professionals and rehabilitation specialists when in a caregiving role transition. In the case of caregivers, establishing a caring dyad between the caregiver and care receiver was found to facilitate interaction between these two people and thus fostering a healthier role transition. Making comparisons was identified as an important process in “situating oneself” (p. 24) in a role transition, and this was identified as important part of the process of a role transition. Developing confidence and coping skills were identified as factors outlining progress in a role transition as these achievements signify actively engaging in the role transition. Skill mastery and identity reformulation were identified by Meleis et al. (2000) as significant *outcome* indicators for the role transition process. In caregiving role transitions, skill mastery was found to occur with the successful act of combining various skills. In the
caregiving domain, these types of skills were found to include: symptom identification, decision making, accessing resources, providing care, accessing the healthcare system, and collaborating with the care receiver. An individual’s ability to allow for a fluid and ambiguous identity while going through a role transition was found to be a positive outcome indicator. Thus, tolerating uncertainty about the process of change was integral to a healthier role transition process as this process was linked to an individual’s ability to alter their personal perspective. As such, altering one’s perspective about personal roles fosters a more effective role transition.

The Underlying Role Change Implications for Spousal Caregivers

As previously identified by Meleis et al. (2000), role changes and transitions involve underlying processes. Thus, a change in role can result in various underlying stressors for an individual. For example, a change in role can be insidious in onset or not obvious to an individual and yet still be the source of stress or strain for an individual. The transition into a new role such as a caregiving role can also create a situation where there are too many new roles and thus create scenarios of competing demands for an individual. The fact that roles are new to an individual often means these new roles are largely undefined. This uncertain nature of new roles can serve as a stressor for an individual. These issues have also been identified in the literature (most often with regard to the Industrial and Organizational literature) and are discussed below in relation to caregiving roles.

Role strain and the impact of role conflict and role ambiguity. Goode (1960) defined role strain as the “felt difficulty in fulfilling role obligations” (p.483). In the industrial and organizational literature, role strain (also named role stress in the literature) is related to the cumulative effects of combinations of role conflict and role ambiguity. Beehr
and Bhagat’s definition (as cited in Jex, Adams, Bachrach, & Sorenson, 2003) of role ambiguity involved an employee’s uncertainty regarding “role requirements and performance standards” (p. 172), in a given scenario. Further, these people are propelled to seek out more role-related information through the participation in their role. Role conflict involves incompatible demands between two or more roles (Coverman, 1989), or an inconsistency between behaviours required for one role (Jex et al., 2003). These concepts combined together will provide the operational definition for role conflict for the purpose of this study.

In the working world, role strain has been found to lead to mental health problems such as depression and anxiety (Rydstedt, Cropley, & Devereux, 2011). Role strain has also been discussed extensively in the Alzheimer caregiver literature (see Edwards, Zarit, Stephens, & Townsend, 2002; Rozario, Morrow-Howell, & Hinterlong, 2004; Burton, Zdaniuk, Schulz, Jackson, & Hirsh, 2003) and somewhat in the ABI caregiver literature (Chronister & Chan, 2006; Gan et al., 2006; Leatham et al., 1996); although stress and roles are often discussed as separate issues in the ABI literature when, in fact they appear to be connected. Accordingly, investigating the nature of role strain for spousal caregivers of individuals with ABI will likely enhance the caregiver literature in this area given that these spouses probably endure different role transitions than caregivers for person with dementias. Although role ambiguity and role conflict have not been identified in the literature in relation to spouses of individuals with ABI, it is conceivable that given the role transitions that these spouses endure, complex role discrepancies such as role ambiguity and conflict may arise. This study aimed to investigate the complexities in these processes of change.

**Role overload.** Role overload refers to having too many role requirements without enough time to complete the requirements of all of the roles (Coverman, 1989). In the case of
spouses, role overload could occur when the number of role transitions involves too many new tasks or role requirements. The concept of role overload can likely be correlated to the concept of caregiver burden where the caregiver can no longer keep up with the demands of caregiving. As mentioned earlier, several findings in the area of spouses of individuals with ABI have indicated that these spouses are required to take on many new roles, such as managing new household tasks, finances, healthcare for the injured spouse, and day to day management of the injured spouse (Florian & Katz, 1991; Gan et al., 2006). Many studies have further identified stress and burden in this population of spouses. Thus, the concept of role overload was applied to the spousal experience and compared in the context of caregiver burden.

**Role reversal.** Role reversal has often been discussed in relation to adult children taking on caregiving roles for parents with chronic and dementing illnesses. Here the term role reversal means that the child (typically adult child) takes on the role of their parent by becoming responsible for their parent’s care and well-being, hence reversing the roles of parent and child. Role reversals may be stressful for individuals as they may not be prepared for the new roles that they must master (Brody, 1990). It is likely that this same phenomenon can happen for persons with ABI and their children depending on the severity of cognitive and physical injuries. Thus, the children of parents with ABI may take on caring roles, or more responsibility in the household such as household maintenance or caring for younger siblings, or even to participate in providing health related care (i.e. dressing, bathing, driving to appointments). Here, questions arise regarding spouses of persons with ABI and whether or not they experience role reversal with their spouse. Are there roles in a marital dyad that can be reversed, what would that entail? Hammond et al. (2011) discussed changes in gender
stereotypical roles for marital dyads who were adjusting to the consequences of ABI, and they found that husbands were more likely to transition into these new roles with ease compared to wives.

**Models for Stress, Caregiver Burden, and Marital Adjustment**

**The Transaction Model of Stress**

Lazarus & Folkman (1984; 1987) developed a transaction model of stress that suggested that stress is experienced when the requirements of a situation are perceived to outweigh the resources of the individual. According to the transaction model of stress, there are three stages that the individual processes; with the first stage involving the first assessment of the situation as having the potential to be excessively challenging, or cause emotional or physical harm. In the second stage, the individual appraises the tools they have available to address the stressful situation. In the third stage, they develop their coping response to the stressful situation. Coping is defined as the measures that people employ to address identified stressors.

Individual differences in appraisals of stressful events and subsequent appraisals of available coping mechanisms likely contribute to a person’s experience of stress. It has been well documented in the psychological literature that high levels of stress can be very detrimental to an individual’s psychological and physical well-being. Furthermore, high numbers of perceived stressful events for caregivers has been correlated with burden (Chronister & Chan, 2006; Chwalisz, 1992 and 1996; Eldred & Sykes, 2008; Stull, 1996). Increased burden likely results in less effective coping and subsequently creates increased health care needs for the caregiving spouse (Gan et al., 2006). Furthermore, research has
identified many stressors that impact spouses of individuals with brain injuries such as increased financial burden, reduced sexual relations, and social isolation. Notably, changes in behavior (executive dysfunction) in the brain injured individual have been being implicated as causing the most stress (Anderson et al., 2002; Buschenfeld et al., 2009). In addition, as discussed in above sections role transitions such as increased family responsibility can lead to role overload and subsequent stress and burden.

**Coping.** When coping is examined as a process that one employs, Lazarus (1993) designates at least two major roles that it serves for the individual and these are emotion-focused and problem-focused. Problem-focused coping functions to reduce the stress between the person and their surroundings by making a change in the person (i.e. learning a skill) or the surroundings (i.e. preventative ideas). The purpose of emotion-focused coping is to change the way one relates to a stressor (i.e. avoidance) or the way one thinks about a stressor even if the stressor does not change (i.e. positive reappraisal) (Lazarus & Folkman, 1987; Lazarus, 1993). In fact it is further identified in the literature that the personal meaning that is associated with a stressor is most important when evaluating coping.

Important findings in the coping literature suggest that individuals who perceive their stressful situation as unlikely to change likely utilize emotion-focused coping strategies and alternatively use problem-focused strategies when solutions can be generated easily or identified (Lazarus, 1993). Eldred and Sykes (2008) found problem solving abilities to be a moderating factor in psychological adjustment of caregivers of stroke survivors. Buschenfeld et al. (2009) found that spousal caregivers of stroke survivors were found to use problem based coping strategies most often and they often attempted to suppress emotion as a form of coping. Blais and Boisvert (2009) found that positive spousal adjustment was influenced by
an “effective” attitude about problems. An “ineffective” attitude about problems refers to
tendencies to see the problem as a threat to well-being, in addition to holding pessimistic
beliefs, lacking self-efficacy, and becoming easily frustrated and overwhelmed with everyday
problems. The outcome of their findings suggested that combining therapy with psycho
education in the areas of communication and problem solving would be most beneficial in
increasing marital satisfaction and life satisfaction for these spouses.

The Perceived Stress Model of Caregiver Burden

Chwalisz’s (1996) research findings in the area of spouses of brain injured individuals
connected the relationships between the outcomes of perceived stress and caregiver burden
with subsequent modes of coping. The Chwalisz (1996) study found that spouses of
individuals with brain injuries perceived their situation as more manageable when they had
previous coping experiences and access to social support. The spouses also perceived their
situations as less stressful when they employed problem-focused coping techniques as
opposed to emotion-focused coping techniques. Furthermore, spouses who perceived their
situation as stressful and successfully enlisted social support experienced less stress-related
physical health consequences. The study produced a Perceived Stress Model of Burden for
spousal caregivers of individuals with brain injuries and it theoretically combined the Stress
Transaction Model (Lazarus & Folkman, 1984; 1987) which is a “stimulus-organism
interaction” (p. 93) model with social support and coping variables to predict the outcome of
caregiver burden (physical and mental health status) using a cross-sectional design. Overall,
Chwalisz’s (1996) model was limited in its ability to identify the process of change within
the temporal relationships of the variables (over time) for these caregivers. Thus, the
caregivers’ changed responses to stress transactions over the course of caregiving would need
to be considered to improve upon this model. This model was not considered to be useful on its own for the present study because it was developed to examine the outcome of caregiver burden, and this study is attempting to explore the process of change as it relates to the combined process of stress and roles related to caregiving.

The Stress Process Model of Caregiving

Chronister and Chan (2006) attempted to expand upon Chwalisz’s (1996) Perceived Model of Caregiver Burden by engaging in a cross-sectional analysis of a Stress Process Model of Caregiving for spouses of individuals with TBI. The Chwalisz (1996) model was expanded upon by adding in additional “exogenous variables” (p. 191) known to predict caregiver stress such as age, gender, functional competency of the care recipient, time since injury and caregiver role (parent versus spouse). Additional “endogenous variables” (p. 192) were also added to the model and this was in the form of specifying types of coping such as avoidant, emotion-focused, and problem-focused methods. Instead of including burden as an outcome variable, Chronister and Chan (2006) incorporated a “second level of endogenous” variables which included burden, skill mastery, and satisfaction. Quality of life was the outcome variable. The model’s hypothesis was that the “exogenous variables” (demographic and injury characteristics) would impact quality of life via “psychosocial resources” (p. 192) and these resources would impact quality of life via one’s appraisal of caregiving. The findings of their model had important implications for understanding how social supports and the utilization of coping strategies in spousal caregivers predict stress experience appraisals and quality of life. Again, as in the Chwalisz (1996) study, the limitations of cross sectional models is that the findings reflect one specific period in time and this method thus does not provide the most suitable findings regarding processes that change over time. Of interest to
the present study is, in fact, the process of change in caregiving roles and experiences of stress over time and thus the Chronister and Chan (2006) model was not used as a basis for developing the method of analysis for this study. It should be noted however that both the Chwalisz (1996) model and the Chronister and Chan (2006) model provided insight into the importance of understanding the role of stress in caregiving scenarios and its relationship to concepts such as burden and quality of life.

**Marital Adjustment Theories**

Various theories of marital adjustment were considered for their potential to provide a theoretical reference or model for investigating the process of change in caregiving for spouses of TBI. Upon reviewing various marital adjustment theories such as social exchange theories, behavioural theories, attachment theories and crisis theories it appeared that behavioural theories and crisis theories may be the most relevant to the situations of these spouses in the present study.

Behavioural theories of marital adjustment focus on the exchanges of actions between partners and this exchange allows for an examination of fluctuations in marital evaluations over time (Karney & Bradbury, 1995). The focus on the particular exchange of behaviours or actions and the constant evaluation of the marriage based on these interactions could be considered to be somewhat similar to the stress transactions models which focus on the interaction between the stimulus and an organism. In a recent study by Hamond et al. (2011) (which was published after the initiation of the present study), Gottman’s (1993) behavioural marital adjustment framework was used a reference for their qualitative analysis. This study investigated the experience of marriage and adjustment for spouses of individuals with TBI. The findings identified that female spouses in the study indicated that their marriages were
on a similar trajectory to Gottman’s (1993) model which described a process of steps in considering the value of a marriage and eventual termination of a marriage. The wives in the Hammond et al. (2011) study appeared to be trapped at a stage where they were considering ending their marriage but they are not moving to the stage of actually ending the relationship and this finding had potential implications for the reasons why spouses stay together after TBI. Overall, behavioural theories of marital adjustment are helpful because they attempt to provide an explanation for the ways two individuals in a couple behave or modify their behaviours and make appraisals based on feedback from the other person in the couple (Karney & Bradbury, 1995). However these theories do not necessarily allow for one individual’s reduced participation in that exchange, as would be the case for ABI injuries in the moderate to severe range. The present study is not investigating the reasons why couples stay together after ABI but rather is exploring the nature of change in roles and the lifestyle within the caregiving experience. Furthermore, the fact that only the experience of well spouses are being examined in the present study presents as a potential limitation for incorporating this theoretical framework. Thus, this framework was not selected to guide the present study.

Crisis theories of marital adjustment attempt to describe the ways that couples deal with stressful circumstances in their lives. The main tenants of the theory include a model of reaction, commonly labeled the “ABCX model” (p. 7) which according to Karney & Bradbury (1995) was introduced by Hill in 1949 and later expanded upon by McCubbin and Patterson in 1982. The basic crisis model discussed in Karney and Bradbury’s (1995) review involves the couples’ initial adaptation to events based on their resources (A), their attempts at re-defining events (B), the additional modification of the impact of the events (C), and the
resulting characteristics of the crisis (X) (see p. 7). Crisis theories of marital adjustment provide an interesting perspective for evaluating adjustment in a marital relationship due to changes resulting from stressful events such as TBI however Karney and Bradbury (1995) suggest that the underlying process of change is not able to be identified by this model. Thus, this model was not selected for inclusion in the present study because the phenomenon of interest is the process of change for couples impacted by ABI.

Overall, some issues were identified regarding the potential for the applicability of marital adjustment theories for the present investigation. The study was not considering the pre-existing dynamics of the couple nor is the central research question focused on why couples adjust or stay together. The present study purports to examine a process of change in the roles of these spouses which more specifically looks at how things happen or change. Many of the marital adjustment frameworks tend to focus on why things happen. Furthermore, it was considered to be a potential problem to utilize a theory about the adjustment of couples when a significant amount of information about the experience of one of the individuals in the couple would not be accessed. The fact that the brain injured spouse was likely no longer engaging in the marriage/relationship in the same way they had prior to the injury also presented as a significant restraint for pursuing the data through this lens.

**Combining Role Transition Theory and the Transaction Model of Stress into a Framework**

The components of Lazarus and Folkman’s (1984; 1987) Transactional Model of Stress state that the individual must perceive a stressor and then come to the realization that they do not have the psychological resources to manage the stressor and then develop a coping response. When one examines role transitions in the context of the experience of
stress, particularly with a lens informed by Meleis et al.’s (2000) theory it becomes evident that aspects of these two models can become enmeshed with regard to the experience of caregivers. For example, Meleis et al. (2000) suggest that a role transition often initially involves a level of awareness about change and this is similar to Lazarus and Folkman’s (1984; 1987) primary appraisal of the stressor. Surmising that one does not have the resources to deal with a stressor and subsequently developing a coping strategy is similar to Meleis et al.’s (2000) process of engagement where an individual begins to develop strategies to address the difficulties associated with their transition. This compatibility between the two theories is not surprising as role transitions were previously identified during the present review as stressful life events that are often associated with the development of symptoms of anxiety and depression. After the process of engagement the individual proceeds into a span of time of developing their new role and this entails encountering critical points and events where the individual continues to experience changes. These changes likely represent continuous stressors that the caregiver perceives and subsequently develops coping mechanisms. Ultimately, each “stress transaction” could be theorized to manifest as the precursor to the next critical point or change in the trajectory of the role transition. Evaluating the stress transactions likely would help to break down the process of role transitions in order to understand how the roles change. The intertwining of the concepts of the Stress Transaction Model and Role Transition Theory thus provide an understandable and logical framework for examining and relating the experiences of spouses of individuals with ABI.
Rationale and Objectives for the Study

Overall the study was initiated in order to generally examine the *process of change in life roles, routines, and overall lifestyle* experienced by spouses of individuals with an acquired brain injury. Furthermore, the examination of the *process of change* for these individuals was guided by a framework that included the theoretical underpinnings of a combination of role transition theory (Meleis et al., 2000) and stress transaction theory (Lazarus & Folkman, 1984; 1987) in order to determine if the framework itself was useful for understanding spousal caregiver (ABI) experiences and support group development for these individuals. The importance of this type of research is exemplified by a need that is evident in the lack of literature pertaining to the specific role transitions of spouses of individuals with ABI (who are significantly amnestic in terms of cognitive functioning), particularly related to themes of ambiguity, conflict, perceived stress, situational stressors, coping methods and potential treatment. Employing a Narrative Inquiry for this research question allows for the overall story of this population to unfold and be reported. In addition, the findings were informed by the spousal caregivers who are the principal stakeholders in this area. Ultimately, the findings represent their point of view which can be considered most beneficial for informing professionals interested in providing intervention, support and assistance. Additionally, there is an extensive literature base for the issues related to spousal caregivers of people with dementias and a less extensive literature base pertaining to the issues of spousal caregivers of persons with ABI. The demographic and life stage differences between these two spousal groups and the differences in cognitive sequelae of the patient populations discussed earlier in the present paper; further provided a rationale for this inquiry. The central research question and one further specific objective that followed from
the central research question are outlined in the following: *Central Research Question:* In what ways do spouses of persons with ABI experience a process of change in roles, routine, and overall lifestyle?

1. Explore and understand the experience of spouses of individuals with ABI in the context of role transition theory and stress transaction theory. Further understanding of experiences associated with role conflict, role ambiguity, role overload, and role strain was also explored. Subsequent coping techniques utilized to address role transitions were also of interest to be explored.
CHAPTER TWO

METHODOLOGY

Qualitative Methods

Qualitative research was developed to help researchers find an alternate way of understanding phenomena, the relationships between phenomena, and the meaning of phenomena. It involves examining data with less restriction by predetermined hypotheses. Corbin and Strauss (2008) define qualitative analysis as “a process of examining and interpreting data in order to elicit meaning, gain understanding, and develop empirical knowledge” (p.1). Meanwhile, quantitative research examines relationships between variables and produces outcome results through statistical analyses. Qualitative research can be considered to have more depth because it has the potential to allow for uncovering meaning in relationships that were not identified by the researcher prior to conducting the study. A qualitative approach to this inquiry was employed because this approach is known to be helpful in understanding processes and the overall research question for this study is to examine the process of change for spouses of individuals with ABI. Most of the previous research in this area has primarily been quantitative, and although this work has been very informative it has often been limited by its static nature because certain methodologies only allow for representations or outcomes related to fixed periods of time. Thus, qualitative designs may offer further insight into the nuances of the processes that involve daily routines and affective reactions of ABI spouses as a function of the complex connections between role changes, stressors, and demands in their environments. Interestingly, some of the most recent research in the area of spouses of individuals with ABI has been conducted using a
qualitative methodology which suggests that exploratory work has been identified as prudent and necessary for this population.

**Narrative Inquiry**

There are many different branches of methodologies that can be utilized to carry out a qualitative research study and narrative inquiry was selected as the mode for this study. This method was selected because it was theorized that the participants’ (spouses’) stories would be most valuable in eliciting information about the temporal nature of events in the process of caregiving; and narrative inquiry allows for the examination and comparison of a number of stories (Kramp, 2004; Reissman, 2002). Clandinin and Connelly (2000) suggest that Polkinghorne’s (1988) descriptive and explanatory methods of narrative analysis are the most successful in identifying the temporal aspects of qualitative story accounts as opposed to other qualitative methods that may just focus on facts that have no relationship to temporal changes.

Clandinin and Connelly (2000) recommend that narrative inquiry should begin with an examination and exploration of the aspects of an experience instead of an analysis and comparison of theoretical concepts. Riessman (2002) considers the object of examination in narrative inquiry to be the story itself. Furthermore, when interviewing participants to collect data, narrative inquiry places emphasis on the way the individuals make sense of and impose order on events that have occurred. It is suggested that for narrative inquiry, longer quotations of the participants’ stories should be kept together in order to emphasize structure, order, and sequencing in informing the results.

In other work, Riessman (1993) suggests that there are five levels of representation in the narrative research process. The first is “attending” (p.10) which is the elements in an
experience that participant actively attends to and brings to their conscious awareness. In the second phase “telling” the participant describes their experience and this is recorded by the researcher. This representation of information is often gleaned through the use of various forms of qualitative interviews. The third phase involves the “transcribing” of the recorded “telling” phase. The fourth phase is the “analyzing” phase and this phase involves identifying significant occurrences and comparing those occurrences across a number of participant transcripts. In this process of analysis the researcher develops a “metastory” by describing what the collective of transcripts portray and the significant elements of the collective story (p.13). There have been various methods developed for analyzing narrative data representations and the method utilized in the present study is described below. The fifth level of representation involves the “reading” which involves yet another level of interpretation as the reader critically analyses the work. Riessman’s (1993) point in designating these five levels of representation was to suggest that the overall story is influenced by the perceptions of those who experience the phenomenon, the researcher who transcribes and analyzes the phenomenon, and anyone who reads the document about the phenomenon.

**Narrative methods for analyzing data.** The narrative method for approaching the exploration and analysis of the data for this study was mainly informed by Polkinghorne’s (1988) viewpoints and theory regarding narrative knowing. Polkinghorne is a psychologist and narrative theorist who described two types of narrative inquiry, descriptive and explanatory. These two types of exploration can be conducted through interviews and document analysis. For Polkinghorne (1988), the purpose of the descriptive analysis is to “produce an accurate description of the interpretive narrative accounts individuals or groups
use to make sequences of events in their lives or organizations meaningful” (p. 161). This type of analysis can be used to link experiences of members in a group. The explanatory narrative inquiry involves asking the question why in order to explain why certain events occur or why they are meaningful. The present study focused on the descriptive premise of narrative inquiry in order to explore the meaning and sequencing of events in the participants’ lives.

Kramp (2004) describes Polkinghorne’s (1995) further expanded theory of narrative knowing which differentiates between “narrative analysis” and “analysis of narratives” (p. 120) as two different approaches for examining the descriptive data. “Analysis of narratives” uses stories to understand a concept or experience where the researcher examines the smaller stories within the larger story to describe these concepts or experiences. By comparing these smaller stories about the experiences and concepts from one participant to another participant’s, the researcher identifies “narrative schemes” (see Polkinghorne, 1988, p. 162) and creates findings that include a developed structure for understanding the represented elements. Hence, “narrative analysis” focuses more on the overall construction and structure of the story of participants. As cited in Kramp’s (2004) chapter which describes Polkinghorne’s (1995) “narrative analysis”, the analysis is described as a method that delineates structure and meaningfulness that may not be evident in the data itself. Here, the researchers attend to the aspects of the narrative such as the plot, setting, and characters in order to construct an emerging narrative that integrates the information as opposed to separating out themes (pp.120). Polkinghorne (1988) describes the process of identifying plots in narrative research as recognizing analogous reports of events that are common amongst a collective of stories. Kramp (2004) defines a plot as:
One of the formal elements of a narrative is a construction by the teller or narrator, whose perspective, or point of view, it reflects. The narrator constructs a plot by selecting and sequencing actions and events, thereby imposing a meaning on these actions and events that comprise the story. This process, often referred to as emplotment, reflects the intentionality of the narrator, who does the arranging or sequencing” (p. 109).

**Breaking down the data for comparisons.** Polkinghorne (1988) points out that people’s stories contain plots and sub-plots, and these levels of plots contain “narrative schemes”. The initial steps in narrative analysis would involve identifying plots and sub-plots, and the next step would involve identifying the “narrative schemes”. “Narrative schemes” are beliefs about events that happen in the past, present and future that are often influenced by personal philosophies or appraisals of social norms. These schemes can influence perceptions of the past events and potential actions taken in the future. “Narrative schemes” are the lowest common points of comparison for the narrative analysis and are most similar to the themes described in grounded theory research (see Glaser & Strauss, 1967). However, Polkinghorne (1988) cautions that these schemes cannot be viewed in the absolute same way as the structured categories described in the grounded theory approaches because the way that meaning is applied through language in stories is different from the ways that meaning that is attributed through the process of categorization.

Clandinin and Connelly (2000) suggest that it is necessary for narrative findings to be compared to existing theoretical literature in order to effectively contribute to the identification of the social significance of the work. Hence, it is conceivable that comparing qualitative narrative findings to previous reported findings in the scientific literature can also
help to situate the stories being identified in a narrative study, thus, creating opportunities for generating theories about those stories. Other methodologies such as grounded theory use similar comparison methods, and for example, Corbin and Strauss (2008) identified theoretical comparison methods as imperative for helping researchers to see more than the raw data itself and to consider all of the aspects and elements of the meaning behind the data points being theoretically compared.

**Self-Reflection: The researcher’s perspective.** In line with narrative (Kramp, 2004; Riessman, 1993), feminist, and constructionist perspectives (Charmaz, 2006), I believe that I likely do not separate myself from the research I am doing and thus must recognize how I influence the process of this research. I became interested in this topic when I was working and fully immersed with brain-injured individuals undergoing memory intervention for severe memory impairments. I was training them to use Smart phones using the principles of errorless learning and procedural learning in order to compensate for their memory impairments. During this work I often met the spouses of the individuals with ABI and discussed strategies they were looking for in order to manage issues at home. It was from these discussions that I learned about the well spouses’ needs for support and services as they appeared worn out (burdened), scared, overwhelmed, and sometimes disconnected from the rest of society. Furthermore, the staff at the hospital that developed and provided a support group for the spouses further corroborated the evidence regarding lack of services for theses spouses. I was informed that a support group was created in response to an observed need in this population, and that there was little theory available for them to provide an evidence based support group program.
I have a personal history of taking opportunities to assist populations who are being overlooked by our healthcare system; either as not requiring services or due to an “invisible” status likely resulting from the lack of acceptance or acknowledgement associated with their plight. For example, in the early 1980’s I was very involved in AIDS awareness education and fundraising. This was a time where there were many societal fears and unknowns about AIDS, and at that time, I felt it was important to help educate my peers and the public in order to reduce fears and increase cultural empathy. Later I focused my energies in the area of dementia and caregiver strain, at that time the literature was just being developed in the area of the “sandwich generation” and caregiver strain for middle aged adults resulting from the unique symptomology (i.e. successive losses, latent grief) that results in a loved one with a degenerative illness. Finally, in 2000 I developed and implemented an art therapy service in long term care facilities to address the residents who were “hardest to serve” due to their problems with communication, ambulation, depression, psychiatric illness, or dementias. In this work, I truly focused on the invisible individuals residing in long term care facilities and developed therapeutic services aimed at improving their mood, sense of self and overall quality of life. I have always felt passionate about these past endeavors and thus, I was not surprised to find myself examining another population of “invisible” and substantially underserved individuals in Canadian society. Given that I am inclined to seek “visibility” for invisible populations, I realize that this self-reflection will help me to understand how I have guided the research and analysis in this study. I am drawn to creative yet practical clinical solutions and it is this premise that additionally guided this research endeavor.

It is noteworthy, that I am also aware of how this research influenced me. The many stories of unpredictable potential health problems suggested to me that I am just as
vulnerable to the potential of ABI becoming a part of my life as any other individual. Listening to the stories of struggle and change after ABI caused me to experience a full range of emotions from sadness to anger. Further, the participants’ discussions of hope, optimism and positivity caused me to reflect on my own problems with new resolve and perspective.

Method

Participants

Spouses of individuals who were participating in or had participated in a hospital-based neuropsychological cognitive rehabilitation program were approached to participate in the study. A total of 15 (N=15) spouses were interviewed, and then it was determined that content saturation was reached. Overall, 17 potential participants were approached to participate in the study and 15 agreed to participate.

The caregiver spouses. The participants’ ages ranged from 40 to 61 years of age. There were 10 (n=10) female participants whose ages ranged from 40 to 61 and five (n=5) male participants whose ages ranged from 45 to 61. Twelve of the participants were married, and three were engaged in a common law relationship, the mean number of years married or common law was 23 years. All of the couples were engaged in a heterosexual relationship. Fourteen of the 15 couples had children; of those 14 couples who had children, 12 couples had children together (biologically) and two couples had children present in a step-parent arrangement (children from prior relationships; and in both cases the children were not the biological children of the brain injured individual). The age of the biological children ranged from three to 29, and the step-children’s ages ranged from 28 to 35. Prior to the onset of the brain injury 12 of the 15 spouses were working. Of the three spouses that were not working,
two were in the process of making career changes. The three spouses who were not working did not initiate employment after the brain injury onset. Of the 12 spouses who were working before of the brain injury onset, 10 returned to work at some point and capacity after the injury. Thus, two spouses who were working did not return to paid employment. The time span that these spouses had been engaged in a caregiving role for their spouse ranged from 10 months to 21 years. One of the spouses had initiated caregiving in the 1980’s, two spouses initiated caregiving in the 1990’s, five spouses initiated caregiving between 2000 to 2005, and seven spouses initiated caregiving between 2005 and 2010. All of the spouses who participated in the study were the primary caregiver for their brain injured spouses.

**Spouses with acquired brain injuries.** These men and women were participating in or had participated in a cognitive rehabilitation program offered at a hospital. This program was a service developed for adults aged 18 years and older (typical age range is 35-65 years) who typically have a non-degenerative (typically non-TBI but not exclusively) neurological condition (e.g., encephalitis, stroke, tumor, epilepsy, anoxic brain injury) resulting in moderate to severe memory impairment or amnesia. As part of the service, these individuals undergo neuropsychological assessment and memory intervention. The intervention involved a systematic training approach through the use of smart phones or electronic devices in order to provide cognitive compensatory strategies that enhance independent functioning.

The ages of the spouses with ABI ranged approximately from 39 to 69 years. The spouses with ABI differed in the types of brain injuries they had sustained. Thirteen of the 15 brain injured spouses suffered from non-TBI while two suffered from TBI and of those two, one spouse had an open head injury and the other had a closed head injury. For a description of the types of injuries refer to Table 1. As mentioned above, these head injuries were
moderate to severe in nature and thus they were accompanied by a range of cognitive and physical deficits. These individuals did experience improvements in cognitive and physical functioning over time through rehabilitation efforts however, they did not return to their prior level of cognitive functioning and most experienced changes in motor and other areas of physical functioning. The most pertinent neuropsychological finding for impairments in the cognitive domains was a moderate to severe memory impairment. For example, the best case scenario for this group of individuals was a moderate verbal memory impairment which means the individual could remember random pieces of information that could not be anticipated whereas the worst case scenario would be a severe verbal memory impairment where an individual could not create any new memories about information, situations, experiences etc. in daily life. A specific example of this type of memory impairment would be an individual who gets into the shower and stays in it for several hours because they do not remember how long they have been in the shower or if they had performed the activities associated with having a shower such as washing hair (hair washing could be repeated several times). Many of the participants also experienced impairments or reduced functioning in the areas of: processing speed, attention, organization and planning skills, problem solving and judgment. One of the brain injured spouses was able to return to driving however most of the brain injured spouses became reliant of various transportation supports such as their spouse, family, city transportation, or community assisted transportation. In the worst case scenario, the individual would not be able to navigate city or community supported transportation because of the cognitive planning skills required and thus they were completely reliant on family for transportation or any opportunity to leave their home. These cognitive changes were severe enough in nature that none of the fifteen brain injured
individuals were able to return to competitive employment. The brain injuries thus caused each of the participants to become disabled and they were all eligible to be declared as having a permanent disability by the federal government and to receive disability benefits. Thirteen of the fifteen brain injured spouses ambulated independently while two had sustained physical limitations due to their injury that necessitated the use of a wheelchair for safer and supported mobility. Further descriptions of the changes in the brain injured spouses from the perspectives of the well spouses are discussed in the results section in Chapter 3.

Table 1
Types of Injury for the Brain Injured Spouses

<table>
<thead>
<tr>
<th>Type of Acquired Brain Injury</th>
<th>Number of Spouses with Injury (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-Traumatic Brain Injury</strong></td>
<td></td>
</tr>
<tr>
<td>Aneurysm</td>
<td>7</td>
</tr>
<tr>
<td>Cardiac Arrest Due to Heart Attack</td>
<td>3</td>
</tr>
<tr>
<td>Basilar Artery Stroke</td>
<td>1</td>
</tr>
<tr>
<td>Brain Tumor (Meningioma)</td>
<td>1</td>
</tr>
<tr>
<td>Limbic Encephalitis</td>
<td>1</td>
</tr>
<tr>
<td><strong>Traumatic Brain Injury</strong></td>
<td></td>
</tr>
<tr>
<td>Closed Head Injury</td>
<td>1</td>
</tr>
<tr>
<td>Open Head Injury</td>
<td>1</td>
</tr>
</tbody>
</table>

Materials and Procedures

**Materials.** One to one semi-structured qualitative interviews were used as the method for collecting the data for the study. The interview questions were informed by the theoretical premises of narrative inquiry. That is, the questions were developed in order to inform the researcher about the social process of change in the lives of spouses of individuals with ABI. More specifically, the questions were derived to elicit the stories of these individuals in order to examine the context of particular experiences and the variances and similarities between the participants. During the interview phase of the study, interview questions were honed in
response to the developments of each interview in order to address emerging schemas for the overall narrative.

**Recruitment.** A list of potential participants’ names and phone numbers was accessed from the cognitive rehabilitation program database at the hospital that was selected to provide participants for the study. These potential participants consisted of any spouse of the cognitive rehabilitation program patient. The spouses were approached by the investigator by telephone about participating in the study. A telephone script describing the study (see Appendix A) was then read to the potential participant. The participant had an opportunity to state whether or not they would like to participate in the study.

**Procedure.** Participants who chose to be interviewed at the hospital were reimbursed for their parking costs ($12.00). The participants were interviewed for one to two hours regarding their experience as spouses of amnestic individuals and their support needs. The interview schedule can be found in Appendix C. Participants were informed (see Appendix A & B) that they may be contacted during the data analysis phase for a 30-minute follow up phone call for clarification of points or to answer any new questions, however, no participants were contacted post interview. Participants were offered an opportunity to review their own transcript; however, all participants declined the opportunity to review their transcripts.

Interview data consisting of digital audio recordings were recorded in digital audio files on a digital recorder and transferred to a firewall protected server. A number was assigned to each audio file to conceal the identity of the participants. Thus, no names were assigned to the separate digital files, only numbers. All files were encrypted. When an interview took place at a participants’ home and the investigator could not immediately
return to the hospital, the digital audio files were kept in a locked filing cabinet in the investigator’s home in between delivery to the hospital. If a participant was interviewed at the hospital, the audio file was encrypted and transferred immediately to the server. The written transcripts of the data have been housed in a locked filing cabinet at the hospital. All consent form documentation and was also housed at the hospital.

**Data analysis.** The recorded interview sessions were transcribed by the researcher. For the purpose of preparing each of the transcripts for dissemination in the results and publication, all of the names of people and places were replaced with fictitious names and locations. Once the transcripts were finalized, NVivo 9 software (QSR International, 2011) was used to manage the data for the narrative analysis. The analysis was divided into two parts, phase one and phase two (see Table 2 and 3).

Table 2

<table>
<thead>
<tr>
<th>Level of Analysis</th>
<th>Method</th>
<th>Story Level</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Analysis of Narrative</td>
<td>Transcribing and Reading</td>
<td>Identifying Small Stories and Sub-Stories</td>
<td>First and Second Level Definitions of Stories</td>
</tr>
<tr>
<td>Contents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Analysis of Narrative</td>
<td>Identification of Narrative Schemes</td>
<td>Identifying Narrative Schemes in Small Stories and Sub-Stories</td>
<td>Most Narrowed Level of Definition of Story Content</td>
</tr>
<tr>
<td>Contents</td>
<td></td>
<td></td>
<td>Confirmation of First and Second Level of Definition of Stories Across Participants</td>
</tr>
<tr>
<td>3. Analysis of Narrative</td>
<td>Comparison of Narrative Schemes</td>
<td>Connecting Schemes between Participant’s Small Stories or Sub Stories</td>
<td></td>
</tr>
<tr>
<td>Contents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Interpretive Analysis</td>
<td>Comparisons to Theory (Framework)</td>
<td>Connecting Schemes and Small Stories to the Theoretical Literature</td>
<td>Third Level of Definition Stories</td>
</tr>
</tbody>
</table>

In phase one (see Table 2); the first part was carried out as an “analysis of narratives” as described by Polkinghorne (1995 as cited in Kramp 2004). The first step in the “analysis of narratives” was to explore the transcripts for the first level of definition of stories. This was
done by breaking down participant transcripts into smaller stories by identifying plots. Once the smaller stories were extracted they were examined for sub-plots or sub-stories. The stories were sorted based on discussions about setting, characters, and plot. For an example of the breakdown of smaller stories see Figure 1 where rows two and three in the diagram represent the first and second level of stories and sub-stories.

![Figure 1. First and Second Level of Definition of Stories: Creating Smaller Stories](image)

In the second step the smaller stories were broken down into narrative schemes by identifying the most salient schemes. In the third step the narrative schemes were compared across participants to identify any similarity in narrative schematic content. At least three or more participants had to identify a narrative scheme in order for it to be included in the results. In the fourth step, an interpretive analysis was used compare the narrative schemes in the smaller stories to the combined stress transaction and role transition theoretical framework described in Figure 2 and to the stress process and role transition literature in general. For the purpose of this study a theoretical framework was developed by combining Lazarus and Folkman’s (1984, 1987) Transactional Model of Stress and Meleis et al.’s (2000) Role Transition theory. This framework provided basis for the theoretical
comparisons of the narrative schemes and events. This framework helped to guide the researcher through considering various aspects of the spouses’ narrative schemes and how they were influenced by internal and external factors such as events (see Figure 2).

Figure 2. Combining Role Transition Theory and the Transaction Model of Stress into a Framework

Further, the small stories (that contain the narrative schemes) were also compared to the existing caregiving literature in the areas of ABI, TBI, dementia, and the frail elderly. The theoretical findings regarding the process of spousal caregiving was then generated from the emerging narrative themes.

In phase two of the analysis (see Table 3); Polkinghorne’s (1995 as cited in Kramp, 2004) “narrative analysis” was the basis for examining the stories. In this phase, the overall structure of each participant interview was examined for flow and timing of narrative schemes and events. The participant interviews were then compared to each other for similarities in timing, context, setting, plots, and their overall process of change. Again the
combined framework of the Stress Transaction Model and Role Transition Theory provided a lens for examining the structure of the process of change for the participants.

Table 3
Phase Two Data Analysis: Narrative Analysis

<table>
<thead>
<tr>
<th>Level of Analysis</th>
<th>Method of Analysis</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Narrative Analysis of</td>
<td>Per Participant Analysis of Plot,</td>
<td>Process of Change</td>
</tr>
<tr>
<td>Structure</td>
<td>Setting, Timing, Change</td>
<td></td>
</tr>
<tr>
<td>2. Narrative Analysis of</td>
<td>Comparing Each Process of Change Amongst Participants</td>
<td>Three Stage Trajectory of</td>
</tr>
<tr>
<td>Structure</td>
<td></td>
<td>Caregiving</td>
</tr>
</tbody>
</table>

Throughout the discussion of the results the small stories and sub-stories are identified as they occur within the phases of the caregiving trajectory. The quotes provided for each small story represent the narrative schemes that were identified and compared between the participants and this information overall represents the findings of the analysis of phase one. The three phased trajectory of caregiving represents the findings of the second phase of the analysis which examined the overall temporal nature of caregiving for these spouses.
CHAPTER THREE

RESULTS

The Analysis in Context: Changes in the Brain Injured Spouses

The investigation involved the analysis of 15 interviews with spouses of persons who had sustained an ABI. These spouses described themselves as being committed to their relationships whether common law or married, and all of their brain injured partners had received or were receiving neuropsychological memory rehabilitation treatment at the same hospital. Some of the participants attended a spousal support group together at the same hospital. The results section describes the well spouses’ impressions of the process or life journey their families have embarked upon since the onset of their spouse’s injury. Initial topics discussed include the story of the illness onset, diagnosis, treatment, and recovery. Many of the participants in the study had young children during the onset of the ABI, and thus the well spouses were able to reflect upon how a health crisis for one parent impacts the children and the entire dynamic of the household. Other important areas addressed included access to health care, transitioning roles, feelings and reactions, development of coping skills, supports, and changes in relationships.

This chapter focuses on the well spouses’ impressions of how their partners have changed since the onset of the brain injuries. The cognitive changes in the brain injured spouses created numerous changes and transitions for the family. All of the brain injured spouses were employed before the injury and none were able to return to work. In fact, many were not safe at home alone for at least two years post injury. The analysis attempts to describe how ABI causes such significant changes in cognition and memory for an individual such that a person’s personality and approach to life appears entirely different to their closest
family members. These changes in various roles for the well spouse often resulted in stress, anger and sadness, subsequently causing the well spouse to seek out or develop different coping strategies. Many spouses determined that there were not enough support services available in the community, and that they were constantly looking for services for themselves, their children, and their spouse.

**About the Brain Injured Spouses**

It is important to have a picture of how the brain injured spouses are different from the person they once were. Discussing how these individuals are different and yet the same is a helpful process for educating the general public about what it is like to live with a spouse who has suffered a brain injury. Articulating how the individual is different was sometimes difficult for the well spouse as the differences seemed to involve a combination of changes in personality and cognitive skills.

*(What else is different about Gord?)* Well obviously he is not the same guy. Aside from his memory, I don’t know, he’s just not the same guy. I mean he is and he isn’t, it’s hard to explain. We used to talk all of the time; he doesn’t want to do that. He used to play a lot of video games, he hasn’t touched them since this happened. He doesn’t even want to and before you couldn’t even drag him away from those things. He’s just very quiet, I mean we can’t even watch movies together because he can’t follow them, so we have to watch these little half hour comedies, because he likes those. He used to read and I did too a lot, and we used to talk about the books, and now he can’t read because he can’t follow the book. After the first two pages, he doesn’t remember what he has read. I mean he’s still a really sensitive guy, I mean
with the pets if something bad happens he cries. He’s still loving and caring. On the same hand, he’s distant too, you know. It’s hard to describe, he’s just not the same guy. (Gertrude)

Changes in self-awareness caused the brain injured spouse to behave differently:

You know just to help reconnect him to that life force, but he’s going to have to connect to it differently than he used to because what gave him a sense of his own power back then was making money. His whole identity was performing beautifully. He was at the highest level of his career and he was succeeding. So this is where, he had his sense of self and he brought that to me…you know, winning chess, winning scrabble. Now it’s funny, he hates losing now, he always hated losing. He doesn’t have a sense of empowerment, that life force, that vital force in him is pretty low right now. It will come back, but it’s going to take a long time I think, and it’s going to be different than it was before…because it’s his identity, essentially his identity has completely changed. His sense of who he is, from what he can remember…I mean I’m holding on to things about his past identity, and eventually you know, we’ll just let them go. (Olive)

The well spouses described changes in personality where the injured spouse now has poor initiation and lack of drive; poor self-awareness stemming from a lack of sense of self and subsequently poor articulation skills. Changes in memory were connected with poor self-confidence. Fatigue was described as a significant problem impeding on the spouse’s ability to accomplish tasks in a day or to get back to leading a “normal life”.

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They did not return to work. All factors combined along with changes in thinking skills such as multi-tasking were the reported reasons why these individuals did not return to work. In fact, none of the brain injured spouses who were discussed in this study were able to return to their jobs.

(So what did he do before the accident?) He was a director at a large company; he had a very high profile job. He hasn’t been back. He has problems with multi-tasking. He would never be able to go back to his job. (Would he be able to do a different kind of job?) I think it would be too much for him. When he has to do his chores, you’d think he do them right away so he could back on the computer but some days he finishes just as I’m walking in the door. (Lisa)

So he’s very different. He was…he loved his brain before. He worked from his brain, he loved intellectual thought. He would rather read Socrates than Bill Bryson. He relied a lot on his brain as opposed to his gut or his sense. He was good at his job because he was very thorough; he didn’t leave any stone unturned. Now he goes there to access information to understand a situation and there’s no information there. (Olive)

Changes in personality and cognitive skills. Positive changes discussed by the participants often focused on a more sociable, helpful or agreeable spouse. The participants described an underlying recognition and understanding that their spouses are not who they once were and may not return to being those individuals. Thus, many changes in personality and cognitive skills were discussed. On positive personality changes:
She was the type of person that was basically confined to herself; a quiet person. Now she is very talkative, in stores she meets people; everywhere we go she meets people. (Frank)

But you know she’s got a much softer side now. Now she’s always been a wonderful person we’ve been together for most of our lives, but she’s got a softer side that she expresses a little more frequently. (Mike)

(So he’s different now?) Oh he’s absolutely different. (How is he different?) He’s different in his personality. Everybody in this neighborhood will tell you that he never socialized or spoke to anybody here. Never used to come outside and now he does all the time. If I’m across the street, he’ll come out, “Hey Nora how’s it going…just looking for my wife”. … Nick never used to help out with the housework and stuff. It was always, you’re the woman you take care of it. I’m not saying that he’s ever been chauvinistic, but now you can’t get by doing anything without him. Now it’s, “Let me make you a cup of tea, what can I get you? I’ll do the dishes if you want to do the vacuuming. I’ll do this and you do that, now wait a minute I saw you vacuuming and now you are dusting, what can I do?” That’s what I hear from him all of the time now which makes life so much easier. (Nina)

Some brain injured spouses developed apathy and poor initiation skills. Other personality changes related to apathy were also discussed:
(Tell me more about how she’s different from what she was before?) She was always pretty easy-going; she was never hard to get along with. She can’t really make decisions. Personality wise she never gets mad, she would get mad before, everybody gets mad. I don’t know, she, well no self-motivation. She wants to watch TV. She used to sew. She’s done some sewing but only when my mother is there holding her hand. She still reads, she reads more than she used to which is fine. She reads the same books over and over. I guess the self-motivation thing. (Kyle)

He doesn’t speak much so he’s very quiet. He doesn’t initiate anything really…as much as I would like him to. I don’t know how much of that is because he has gotten used to being taken care of, and I think there has always been a part of Oscar that just wanted me to take care of him anyways, so he’s got his wish. I think there was part of Oscar that said, “Oh my god, if I didn’t have all of this stuff that I had to do I would just sit and watch TV all day”, which is what he’s doing. (Olive)

The participants discussed their spouses’ problems with fatigue in relation to apathy and lack of initiative. The following excerpts discuss the implications of the brain injured spouses’ fatigue:

And Carl, I know it’s not his fault because what has really been affected with him is his initiation, which is common in brain injury patients along with the short term memory, and then there is his fatigue. He wants to try to do a lot, like his exercises, his volunteering…doing even those two things for him, he gets tired and then all he wants to do is watch TV…and that just drives me crazy. I say to myself, it’s not his fault, and I try to ignore it…Especially when I remember what he was like, in terms
of getting stuff done. He was just ...he’d be up at 5 in the morning and by 12 o’clock he’d already had a full day. Now he can barely fit in his exercise program. (Claire)

(What’s the most significant difference in his personality other than being irritable?)
We have some neighbours he is really good friends with. They’d be outside talking, it was constant. On the weekend, we would have a BBQ in our backyard or their backyard. He just doesn’t seem to take the initiative to do that. He’ll see them out there and say, “oh I’m just going to have a nap” and he would have a nap instead. He’s more tired. And it’s all the medication he’s on. (Heather)

On the impact on thinking skills:

He’s changed a lot, but you know his sensibility is still there. I can tell that there’s some humour, he will notice things, he’s still perceptive and he notices what’s going on. He will make a wry comment or he’ll make a joke, so all of that is still there…it just doesn’t come together as much. It’s almost like his old self…he’s not connecting. It’s like, from a brain perspective if we used computer terminology, there’s sort of this white noise, white noise, white noise, scramble, scramble, scramble of stations and then all of a sudden oh there we go and there will be a piece that will happen like he will go and fill the dog’s water dish. (Olive)

(So what changed?) Well the way she was on her own, a mother that took care of everything, she is the complete opposite now. She needs direction now; she used to make decisions before, now she relies on us for decisions. She used to be able to do whatever she wanted, go out, take the kids wherever…now she relies on me for that,
it is the complete opposite… The biggest changes are definitely her personality. From a person who was very professional in what she did and organized to something completely different. It is the opposite now. Is it bad, no I wouldn’t say it’s bad, it’s just a big change. (Frank)

On memory changes and the subsequent impact on self-confidence:

His quietness, because he is unsure. He doesn’t talk like he used to because he is afraid he may have said it before; so his quietness with me. When the US invaded Iraq and they revealed there were weapons of mass destruction, we had many heated conversations at the dinner table. We often did about two different sides of an issue. I miss those two different sides of the issues, I like that we had different opinions. I don’t get much of his opinion now. One he wants to keep me happy, I can tell him to give me his opinion but I also get tired of reminding him of that too. He doesn’t have as much to say. (Anne)

On changes in life perspective and interests:

He is different in a better way. He is different. Before he was very anal, he was a workaholic, he didn’t enjoy life. When he enjoyed something he worked hard at it, like skydiving. He wouldn’t just go sit on a beach that was just too boring. It had to be something that was an adrenaline rush; he was getting that from work, because work was number one. Everything was work, and then he had this accident. He didn’t
really have a great sense of humour. He didn’t really spend much time with friends or family, he would rather be working. Now it’s unbelievable but he’s not the same. He is the guy I married but he’s not the guy I fell in love with. So I have thought of those problems. (Lisa)

Different yes. Different but the same, like I still feel like he is my husband. You know we have been married 35 years but we have been together a long time and he’s much more social now. I remember when they took him into the hospital and there was his underwear on the floor and the nurse saying do you want to take those home and I remember thinking this would have been his worst nightmare, to be in a place like this with no clothes on and all of these people around him. And now he’s social, he never used to like to eat out because he thought restaurants were dirty. He’d eat out every day now…and shopping that’s the worst. It used to be I’d want to spend and he’d want to save, now it’s like we both want to get things, so that’s the biggest challenge now, balancing the spending. (Elaine)

**The brain injured spouses’ reactions to the brain injury.** The participants discussed how their spouses reacted to having a brain injury. The overall theme that emerged was that the brain injured spouses appeared to have adjusted to their injuries; however they lacked insight into the totality of change. Thus the participants were left feeling uncertain about how their brain injured spouses truly feel about their brain injuries:
(Has he shared with you how he feels about all of the changes?) Not a lot. I have to start that conversation too. Sometimes I put my fears on him but when you start that you realize that somehow he has found a way to settle in to it. He used to worry about helping the girls, saying “how would I get to them if they needed me?” He doesn’t worry about those things now. I don’t know how he found a way but most people at the spouses group say that those changes came about, that it happens along the way. I don’t know if time makes it different or he sees that others cope. He doesn’t share a lot. (How is he coping?) I think he is coping very well. He was the type of person who got things done, he never obsessed about things just went out and did it. He just did it and that is what he is doing now. I make a bigger deal of things. He makes it clear that he has what he wants; he has his family and me. (Anne)

(Has he ever talked to you about how he feels about having had a brain injury?) No, and I wish he did. You see that’s why I say, it sounds silly…but I know he knows he had a brain injury but I don’t think he knows how he was before. He knows he’s had a brain injury obviously. But he doesn’t look back. He doesn’t dwell on the past, saying, “I had this,” or “Oh poor me.” I asked him once and his comment was, “The eye cannot see itself.” That was pretty profound and deep. (Lisa)

Overall, the well spouses found themselves trying to re-connect with their partner after the injury. The issue that arose was that it was difficult to connect with someone who was not connected to themselves because they were not quite aware of what parts of
themselves they had lost. The well spouses felt that this reduced insight helped the brain injured spouses to cope.
CHAPTER FOUR

RESULTS

A Context for Role Transitions: Common Issues Impacting the Spouses throughout the Caregiving Process

Right away, with the initial diagnosis of the illness/injury, the well spouses were thrown into the role of caregiver. In fact, many new roles emerged in their lives. Overall, the data illuminated a process of developing as a caregiver for these spouses and as this process emerged the second phase of the analysis identified a division into three phases to help explain the experiences of these caregivers. Hence, the three phases developed through the analysis of this data are: the embryonic caregiver phase, the immersed caregiver phase, and the modified caregiver phase, and these phases will be discussed in the following chapters.

There were some changes and transitions however, that were discussed by the spouses throughout all the phases of caregiving. Therefore, the following issues discussed by the spouses were found to be present throughout all the process of caregiving. The spouses may have focused on these issues to differing degrees depending on when the problems arose and on their capacity at the time to address or cope with these problems. It emerged that these were continuous concerns that did not seem to have final resolutions but rather became matters to address during all stages of the caregiving process. These issues impacted the feelings and were connected with the role transitions experienced by the well spouses.

Financial Issues and Decisions

Many participants discussed the negative impact on their finances since their spouse’s injury. They discussed worrying about maintaining their current standard of living and
having to make adjustments in spending, including living costs. Some participants worried about future spending, investing, and retirement planning. A significant issue for some was affording continued rehabilitation costs that were not covered by their benefit plans or OHIP. There were many concerns about finances:

(What did Oscar do before?) He was in a period of unemployment. So he didn’t have any employment at the time of his injury, so there wasn’t any disability that came through. So I had to go into financial … I had to take care of all of that suddenly. (Was that a struggle?) Oh yah, it still is. Things have settled in…it took awhile to get my bearings and to notice that we were ok. It took a while to get that feeling. I think there’s the financial stress; I think that you probably hear that a lot. Again, we’re fortunate, we have a home, we are able to pay the mortgage, I’ve got my business. Even in all of this I was able to bring my business up. It wasn’t the intent but you know I’ve basically done that in two years. The first year it was pretty part time, the first year into the injury I was just trying to keep it, hold it, hold the ground that I had made. His mood has changed in the last three years; he’s become a lot more like he was pre injury. Physically he’s a lot different than when he first came out of the coma and started walking again, he’s slowed down a lot. He could still use a lot of physio. But that class costs money and I don’t mind paying the money because it is money well spent. But I can’t do it every day. Physio isn’t covered so we are paying for a trainer at the gym. So all the trainer does, because Oscar knows he is a trainer and what that means, so these guys are essentially just setting Oscar up on the equipment and letting him do the equipment and reminding him what the next thing is. The only reason he has that person there is so that he’d go to the gym for the appointment. But
if he had a physiotherapist, that professional relationship, he would be more responsive to it because he gets it. So money…so I do what I can and we budget a certain amount for this, but it would be great if he could do piano three times a week. As it is, we are lucky if we can do once a week. (Olive)

(So you’ve lost his income and yours?) He was the primary bread winner and he made really good money. He also had perks, like cars and gas were paid for. So all of a sudden, all of that is gone. So thank goodness he had a good long term disability plan that he had paid in to, which pays us about 60%. But at the end of the day, we are functioning on about 50-60% of our income but our expenses haven’t changed. It’s really just become a matter of taking from Peter to pay Paul and vice versa. About five years before he got sick we had moved into a big home, much to my…well I didn’t want to do that, but we were both doing well in our careers…so we decided to go ahead with that move. So all of a sudden I have this huge house with huge care and costs and 50% of our income. I’m thinking how are we going to survive? (So you have to keep the ship afloat?) Yah. So I said to myself, whatever it is, however I need to bring in money, I’m prepared to do that. Recently, guilt came into this financial situation for me, because I’m thinking about moving on, in the sense of… even if I started to work part time, or even… in housing the foreign students I will have to spend money on fixing up the basement. We have a big home and instead of going through the upheaval of selling it, I could maintain the property and still give Carl some stability. (Claire)
Some spouses felt like they absorbed their financial changes well and they were able to minimize the impact on the household. For these spouses, they acknowledged that their incomes reduced however, they did not find the change to be a significant stressor:

I was lucky that I was in a job where I was reasonably well paid. She did bring in a little bit of money before she got sick but we were paying a mortgage and when she got sick we were 60 per cent paid against the mortgage. So it was ok and my parents helped out a little bit and so did hers. Again we were lucky because she hasn’t really been on any medication, had she been on a number medications that’s a huge impact on finances and so on. Well I’m not going to spend sleepless nights on it but… basically what I did is I got myself life insurance after this happened, so there will be funds if something happened to me. I retired officially two years ago, but I am still basically still working full time almost, four hours a day, five days a week. I work 4 to 8 and I am on call all night every night…which is a win win situation at work because no one else wants to be on call and it works out for me, it is financially rewarding. Probably I will be doing it for another two years and then I will have to re-evaluate. (Doug)

(What about financial concerns?) That will be ok. Henry will go to long term disability through work. So that will be all right. We’ve had a hit in salary as it is now. He drove around a lot for his job so he had a car allowance, so he got $500/month flat and he had lots of overtime. So we already have had a hit of $1000-$2000 dollars less a month, and we’re fine. I’m just; I’m trying to sell my car, because
I don’t need two cars. There’s no point in paying for two cars. I was watching one of those shows one day about debt, and things you can reduce. So I thought I don’t need two cars. If I get rid of the more expensive car, and Henry’s car is a lease so I will have to keep it for now. We’ll be fine. It’s not financial, it’s more that there’s too much stuff to do in the house. (Heather)

Interestingly, there were a couple of spouses that felt that they had more money than they anticipated after the injury:

(So have there been any financial implications from this injury?) Yes, positive ones. My wife would spend money like you wouldn’t believe. Now she doesn’t. She could spend money faster than I could make it, now she can’t. She still has credit cards but they’re in my name. She used to hide stuff from me, rack up credit cards and we’d get stuck with these bills, now she can’t, so that’s good. She can’t drive so she has limited access to shopping. (Kyle)

(Are there financial implications?) Well, I get paid still. So that (the finances) have improved too…because at her last job she had a disability plan, we didn’t expect that. She didn’t have a pension, so we knew we would rely on mine, so now, in addition to my retirement money, we get her disability. So financially we are good, now there are little extras like trips to the hospital etc., but there are fewer expenses now because Beverly used to drive all of the time, and she would spend money. Now the only time she spends money is if she is with me or the girls so that’s good. So it’s not like she is spending money all of the time, just on necessities. So financially it is probably better now than before. (Bill)
Mental Health Problems

Since the onset of their partner’s injury, many of the spouses experienced symptoms of depression such as sadness/low mood, anhedonia, hopelessness, difficulty sleeping, fatigue, overeating or an inability to eat. Various stressors contributed to the symptoms of depression; however, the initial brain injury onset was largely a contributing factor to the symptoms as this was the initiation of a process of loss for these families. Symptoms of anxiety included an inability to control worries, disruptions to sleeping and eating, restlessness/agitation, and worrying about a number of factors in their lives. Some of the spouse’s symptoms of depression and continued through the years of their partner’s recovery, where they eventually sought out or continued professional help for their symptoms.

I broke down once and I asked the doctor to send me to somebody who I could speak to and maybe relax, and it didn’t go very well. I guess because I’ve had so much attention for Nick when I needed it, that when they said they could fit me in six weeks and then again in another six weeks, I said, “Heck no.” That’s when I found my own alternatives like talking to my girlfriend, going to massage therapy and writing.

(Nina)

How did I cope? I cried a lot and I yelled at my poor children. I did feel very suicidal and didn’t recognize it at the time. I did have post traumatic stress syndrome and again didn’t recognize it. The insurer sent me to a psychologist who diagnosed it and of course I got stuck on antidepressants for years and years and years. I did go to a psychiatrist for a long time that was helpful. I was really lonely, really frightened, and
really confused. I was really overwhelmed and I still am. Not as much, but I am.

(Janet)

I’ve been handling it pretty much on my own. I did go to the doctor about two years ago for sleeping pills, but he wouldn’t give them to me. He said I had to learn to cope. I did go on antidepressants for 6 days in March 2008. One of the doctors at the rehab hospital thought I should take them for a few days, because I needed to calm down because I was yelling at them all (laughs). The doctor had wanted to send him home, and I guess at that point, I just snapped. I did take the pills but I didn’t find that they did anything for me. So I don’t take pills, I don’t drink, some people have a glass of wine, I never did that anyway, so why start that now. I think I’m just too busy to think about stuff. (Gail)

Physical Health Problems

Overall, the spouses indicated that they did not feel that their situation had directly impacted their physical health. Some did have minor complaints however most discussed weight fluctuations and hypertension. Some had developed sleeping problems, and a few had developed more serious diseases such as, diabetes and cancer.

My health, well I’m 13 years older (now), I didn’t take care of myself for a long time. I didn’t exercise, didn’t eat properly. It’s hard to get back to that, you can’t get what you’ve lost but you can build on top of it. Thankfully I’m not in my 80’s where it would be impossible. (Janet)

Some participants discussed problems with sleep and fatigue:
(How has your physical and mental health been?) Well I’m fine, but I have been diagnosed with fibromyalgia since this. My sleep…and that came out because of a sleep disorder. That occurred, probably shortly after this whole thing started. I was still on, I was on high alert, I wouldn’t know if Oscar would get up in the middle of the night and try and get back to Orr. So when I was getting up in the morning I felt like a Mac truck had hit me and I was stiff and sore and my muscles were aching so I thought I had rheumatoid arthritis because it runs in our family... I think it’s common that spouses of folks…they probably don’t see a doctor as much as they should, it was like yah whatever. I was like, I’m fine, I’m fine, I’m fine, I’ll see a doctor next month kind of thing. But the sleep thing was starting to get to me. The rheumatologist did her trigger point diagnosis and said she figured this was fibromyalgia. So I’m fine, you know I’m fine, but that is a stress. There’s been research that connects that with stress and trauma; it’s one of those kinds of diseases, but who knows. Yah it’s taken a toll, but I’ve also taken care of myself and all of that. (Olive)

(How has your physical health been since this happened?) It’s better now, but I had lost 30lbs. I was really skinny. I wasn’t eating, I was at the hospital all of the time, smoking like crazy and drinking coffee. I have had a physical and I’m ok. I still smoke which is a bad habit. I don’t sleep well. (Gertrude)

On developing weight and hypertension issues during the stressful changes in roles:

(How has your physical health been?) When he first got sick I was so busy running him around I would have half a sandwich here or there that I lost 40 pounds. I think I ate little bits and went so I was really thin. Then I started drowning my sorrows in
food whenever I was feeling miserable I would go to the grocery store and bring home sweets, so I gained weight. I have a cholesterol problem, my cholesterol is up, and my weight is up. My health is somewhat affected by that. I had a scare with a mammogram; I had a cluster of cists. It felt really scary going through that because I thought how am I going to manage if it gets really big? How will I care for him and cope with me? But it was fine and now I just have the cholesterol problem. (Anne)

(How has your physical and mental health been since this happened?) Fine really, no concerns. I go to the doctor once a year unless there is something wrong with me, and they said I’m good. Well I need to lose some weight, l lost 20 pounds last year, so I need to lose 20 more, I’m working on it. But I’m fine. (Kyle)

(How has your physical health been since this happened?) OK. I’m overweight because of bad eating. I had surgery for a fibroid. Then just, fatty liver disease and I overcame that. It’s just… you know what might crop up in anybody’s life. I’m thankful that nothing has been really bad, but I wish I never had surgery. (People have mentioned that their weight has fluctuated, is that what happened for you?) Well yes, it wasn’t a lot of weight but my family made sure I ate. I’m not terribly over what I used to be, maybe 25 pounds higher in the last five years. I’m sure a better diet and a little bit more exercise would take care of it, but it is all about the lifestyle that you live now. (Nina)
Some participants discussed new health problems that they have developed. It is unclear if these particular problems are related to the effects of chronic stress, poor lifestyle choices, aging; or if they are a combination of all three factors or random:

*(How has your physical health been since this happened?)* I think it is ok. *(Do you have any health concerns that have developed?)* No I think they are coming on with old age, like I’ve got diabetes now and I never had that. I’m sure that has nothing to do with him. (Lisa)

*(How has your physical and mental health been?)* Well I had cancer two years ago; you know all of the woman’s parts had to come out. Now that was hard because I was going to be gone for a week, and my son was off at school. I ended up having Edward’s father come up, so that’s something you have to think about too. The doctor didn’t want to put it off; I wanted to wait until my son got home. But it couldn’t wait, it was ovarian cancer and it was pretty yucky. So then I went for chemotherapy. (Elaine)

I mean, definitely my mother’s been at my place and very helpful because I had heart surgery myself three years ago. So that was a big change too. I didn’t know what was going to happen, so I had to tell my daughter a lot of stuff, prepare her, she was going through that again, that emotional thing. I had a heart murmur, so every year I had a physical to check it and that year my aorta had dilated to a risk that it could explode at any time, so I was booked for surgery for a mechanical valve. (Frank)
Support Needs Identified

The spouses discussed the different types of topics and information that they felt would address their needs throughout the process of caregiving. They discussed needing information about services, finances, and other practical everyday issues. They also indicated that they needed support regarding their feelings and their ability to engage in the caregiver role for their spouse. The discussed the various types of information that they were looking for:

Information about resources, information about the system and how to access resources... I mean I kind of figured all of that out. The financial kind of...I know that the social worker has done a lot of topics, there is sort of the financial angle of it all. Because... if the women are the spouses, they may not know anything about what is going on in the financial scene in their family and all of sudden this happens and you know. So even, you know how to invest and how to take care of the family. (Olive)

Learning about what’s in the community. My wife has always refused to have anything to do with the disability bus because of her personality, but it is nice to know that it is possibly available, should you need. The presentations at the hospital have been of interest, for example by the nutritionist about vitamins was quite excellent. The neuropsychologists’ presentations were quite good…We discussed in the spouses group how it would be nice if there was a central organization where you could get this information or it was made available. It would be nice if people were taken for surgery and when they come out they are given a list of places to call or for someone to explain what is available. I suppose it is tricky because there is not a lot
of money around for this. It’s just a constant struggle, so that is basically where we are at. (Doug)

Well definitely, understanding feelings that one goes through, learning where to go for information, even to this day we know there are a lot of support groups, but a list of the support groups, what are they, provides us more. I think to have another guest speaker [at the support group] to help us understand more about the brain. To help us understand more about what’s happening, what are the challenges that happen? The neuropsychologists’ few sessions were very informative and it definitely helps. I think speakers from different fields, what challenges have they experienced and what have they done, and to know what is out there for support, what is the easiest way to get there…we’re lucky that Francesca was able to take mobility right away. Other people are on a waiting list and are being denied service. I think it has to do with when you fill out the application and what you put in there. (So it has to be filled out in a certain way?) Yah, I guess. I think that if someone has had a brain injury and it has been assessed, the mobility should be provided. It shouldn’t have to be that there person was physically impaired. You know if they can’t get around then they need support. Filling out the applications, where to go, all of these information sessions do help. (Frank)

**Needing a forum for support.** Many of the spouses indicated that they would benefit from various types of formal support such as individual or group therapy in order to share feelings, learn about coping skills, and to feel connected to others. Many of the participants
in the study had participated in individual or group treatment or both during their caregiving trajectory. Thoughts about their social support needs are discussed below:

I’d just like to hear about other people’s experiences, people may have odd experiences or otherwise. Ways that people have been able to cope would be a good discussion topic. You know I just developed strategies along the way. I read a couple of pamphlets, but I didn’t try to look up information. I just tried to adapt to Beverly, I listened to the doctors and what they were saying. There was a lot of observation and trial and error. (Bill)

Probably knowing that there are other people out there that have the same feelings that you have…so you don’t feel the guilt. You know there are other people who are experiencing this and they may have tips to help you cope with things. You know…this is what I do when I feel that way…you know that support, knowing you are not the only one. (Heather)

The spouses indicated that they needed to make personal connections and derive a new sense of community in their lives. Many discussed this phenomenon in the context of support group participation because they were hoping that a support group would provide a source of community for them.

I think for me, at the point I was at when it started that I already knew a lot of things. It was more about the connections than the learning for me. For some people though,
it was about the learning, they would discuss trying different things. It was just the emotional level that I needed. (Anne)

I’m of the nature where I’d like to travel and it would be really great to connect with another family to travel with, and I’ve thought about this. Would it make sense to have not just…the support group you can go and talk and stuff which is great, to have that emotional support and stuff, you get some ideas and to be making that sort of exchange. But also just on a really practical level, like, “Hey, we go to the gym on Wednesdays, what about Oscar and so and so, if we live in the same area, hooking up and doing stuff together, or us doing stuff together and the guys hanging out while we do.” You know that kind of thing. It’s really building a community that I see, finding folks that you can build community with and how to do that. If the support group could actually be umm… or if individuals in that support group can be part of community, you see what I am saying. That makes a huge difference. And it could be that if the support group was every Wednesday night, like hey, everybody brings a casserole that they’ve baked and we carved it into different chunks and people take it home. That makes it more than just a support group, it makes it a community…then there is something else going on there, like we are helping one another. (Olive)

It is good to hear other people’s stories because you think you are alone. You really do think it’s only happening to you. It’s easy to talk to people when everybody is having the same problem and then it’s good to hear various solutions form people. I think you get a little bit out of it not matter what you go to. Even ours…if we end up
having a bitch session about the government…for the hour that you are there maybe
you’ve learned something, something you can take away. (Lisa)

A desire to help others in addition to receiving support was also identified as an inherent part
of enhancing connections and a sense of community:

Sometimes being able to give advice because you have been at it for 20 years while
others are just getting through three to five years. Also getting away from everybody
for two hours, you know it’s that sort of thing. (Doug)

Overall, many spouses described having similar transitions (i.e. changes in roles) and
feelings (i.e. loss, sadness) and they expressed a need to share those experiences with people
who had also experienced the same thing. They indicated that hearing how others dealt with
these experiences would be helpful. Furthermore, the participants alluded to an underlying
process that occurs where they feel that the way they connect with others and the world
changes from their previous pre brain injury way of connecting with others in life. This
process includes experiencing distancing in relationships with people who were once close,
leaving the spouses to feel alone and in need of new connections and support.

**Concerns for their Children**

The issue of the impact of the brain injury on the children was addressed by many of
the spousal caregivers. Many of the spouses reported that they discussed this problem and
various strategies for improving their children’s coping at their support groups. This
emerging theme further exemplifies the support needs for the children in addition to the
feelings of inadequacy related to the spouses’ difficulties in supporting their children particularly in the early stages of the brain injury. Some of the spouses discussed their concerns about how their children were coping and they subsequently looked into formalized support services or individual treatment for their children. Other spouses tried to help their kids by being supportive themselves or by trying to modify their home environment to be as close as possible to the way things were prior to the injury.

**Feelings of grief and loss were complicated for the children.** Overall, the spouses reported that their children experienced feelings of grief and loss. They explained that grief was complicated by the confusing feelings of being happy your parent had survived but feelings upset and frustrated about their limitations and how the dynamics of the household had changed. The spouses expressed concerns about how their children were handling the losses due to their parents’ brain injuries however; they most often indicated that they relied on their child’s ability to adjust in the context of the family and social supports around them. It was difficult for many of the children to understand and accept their own feelings about their parent’s injury and its consequences to their households. On ambiguity in the grief process for children:

Trying to figure out Owen (eight year old son)…that was a whole other scene, Owen was trying to figure out what…ok daddy’s coming home and now this is the daddy he’s got, it’s hard to grieve because it is ambivalent. There is this whole ambiguous grief because you got your dad back but you don’t got your dad back. He was upset. At one point he was crying in bed, he would work himself up in bed…he wouldn’t come out and say I’m upset because of what is going on with dad, he would keep wanting to do things that he wasn’t supposed to do and I would say “No, no, no, no,
no…” Then he would get really mad at me and he would get frustrated and he would start crying and then he would let it out. Which is understandable, and I knew it was going on so I just let it happen and so then he’d eventually have a cry and let it out, and I would listen. At one point he said, “Why didn’t daddy just die?” That was hard to hear. I didn’t answer his question, I said, “That would have been simpler in a lot of ways, wouldn’t it?” It would have been clearer … because we could have just been sad. Everything became about Oscar’s recovery and Oscar’s injury. (Olive)

(How has your son dealt with this?) When it first happened he was in his first year of high school. The first thing he said to me was “Am I going to have to leave school?” You know I think he thought we were going to be poor. I remember him saying to me, “My father is dead to me,” and I remember being really angry at him. So I talked to my brother and he said “You know what, he is, the father he knew is dead.” (Elaine)

I think what’s hardest for the kids, and by virtue of that for me is that I have to reorient their vision all of the time, is you know, “I wish daddy didn’t have a stroke, then we could do this and we could go to Florida, or we could have done that.” There’s lots of brokenness that comes…especially when daddy doesn’t understand the kids or he gets angry more easily because of his own struggles. There’s the whole anger part of it that goes along with it the depression, the sadness, the resentment. There’s lots of impact. (Inga)
There were changes in interpersonal dynamics between the brain injured spouse and the children. These interpersonal dynamic changes seemed to lead to situations where the children engaged in arguments with the brain injured parent even though they were told that the brain injured parent could not control their behaviour or emotions. Over the course of the caregiving trajectory, the participants often felt limited in providing support to their children as they were overwhelmed with the task of caring for their brain injured spouse. The well spouses discussed the ways that they were able to help their kids develop coping strategies for difficult behaviours exhibited by the brain injured parents.

Well the kids get annoyed with her sometimes. She taunts them sometimes. They’ll be doing something, and she’s like a kid herself sometimes, so she’ll be standing behind them and hovering over them, following them, asking ”What are you doing?” or telling them how to do it. They’re not really like kids anymore, they are grown up, and they’re like “Get away from me.” They get angry with her. I tell them it’s not her fault; she doesn’t know how annoying she can be. She does it to me too. For the most part they are pretty good with her, they know it’s not her fault and there’s nothing she can do about it. (Kyle)

The younger one was very angry with her father, they were very close. They had a similar kind of energy, so they used to play a lot. So she was very angry with him. I was very fortunate, because she had a very close friend whose mother took her under her wing and cared for her. They both (daughters) just needed that extra caring but there are only so many directions you can go. (Janet)
Well the older one has basically said to me “I never had a mother, I never had somebody to talk to about girl things and so on,” she said her friends could go shopping with their mothers. She also didn’t get along with Denise too well because her friends would call her and Denise would not remember to get the message to her and my daughter would take this very personally. There were major issues between them, fights etc. Now that she has moved out I think that things are getting a lot better. (Doug)

The stories of complicated grief in the children as discussed by the parent participants indicated that there is a need for support in the community for these children. Some of the spouses were able to address their children’s support needs to varying degrees throughout their spouse’s illness. Relying on the children for managing roles in the household may have contributed to their feelings of stress and complicated their grief. The well spouses ended up developing new expectations of their children such as helping out more around the house or with tasks related to caring for the brain injured parent.

Now she (daughter) is driving and that is a big help because she can do the groceries or take her mother to appointments... At times I feel like I am pushing too much on her too, and she needs her life too, the doctor at the rehab hospital has said you know she is 20 years old, you kind of have to let her go… but at times you know everything is on me and it’s like help me out a little bit here. At times I look to her and she’s says I have to go out tonight and tomorrow night and I’m like, come on I need some help here. So at times there is a bit of friction, so I rely on her for help. On a Saturday, I will say to them (kids) “Let’s do some cleaning around the house, you know don’t
leave it all to me,” or I will ask them to clean their rooms, do some stuff as well, and they will help. (Frank)

Many of the spouses discussed several issues that they thought were impacting their children such as worries, loss, sadness, anger, understanding ABI, changes in family dynamics, and so on. They also indicated that they did not have enough time to address their children’s adjustment needs in a way they felt was adequate. Regardless of being biological or step children, the spouses reported that all of their children experienced feelings of grief and loss due to the acquired brain injuries experienced by their parents. This grief was described as ambiguous because there was confusion between feelings of happiness for the parent surviving the injury and feelings of sadness for the way the brain injury changed the parent. Overall, the children reacted to the brain injury in different ways.

**Feelings of Loss are Continuous**

All of the well spouses discussed various feelings they have experienced since their partner’s injury. Loss was a feeling that was touched upon by all of the spouses who were interviewed. Loss was described as an open ended and ambivalent process because the participants did not really know the extent to which their lives would be impacted or changed at the time of the injury onset and onward. The spouses indicated that they felt a sense of loss when they recognized various deficits in their spouse’s cognition. The changes in cognition that were integral parts of prior functioning such as decision making abilities, parenting abilities, conversational abilities, physical abilities and so on subsequently translated into significant role changes and losses for both spouses. The recognition that the changes were more permanent did not usually occur immediately during the illness onset but occurred
when the participants observed the ceiling effects of recovery (a plateau) about a year to two years after the injury.

It’s just tough. I love him, but he’s not the guy I fell in love with. Luke used to be, well it shouldn’t matter what he looks like…but he used to be this tall thin guy, great manners…and that’s one of the things he had that he doesn’t have now is manners. Like eating, it’s like he’s never seen food before. Its little things like that, we just work on them. (Lisa)

I went through an awful grieving period because I would pull over in the car and start crying uncontrollably, because I was thinking the person I know is actually gone, and I don’t even know what I’m dealing with right now. And you are totally alone. (Claire)

Before the spouses can reconcile the losses they have endured, they have to come to understand that their spouse is a different person. One spouse describes this process as she begins to think of herself as a married widow. She points out that her husband’s cognitive changes have lead her to experience loss along with conflicted feelings about the state of her marriage. During the interview process many of the spouses commented on having negative thoughts such as how things may have been easier if their spouse had passed away. Fortunately, these spouses were aware that these were common feelings to experience in their situation. The following excerpt exemplifies the ambiguous nature of the spouses’ grief in response to loss.
This just led me to that article and it talked about all of that and how the outside world doesn’t understand because they see the person and they’re like well, what’s the problem? That’s how that person is really, so non-existent in the relationship and you are a married widow. I thought that’s perfect, that’s exactly what we are, married widows. (Claire)

**Communication, conversation and loss.** Many of spouses reported missing the way their spouse communicated to them on an emotional level while others longed for more conversations and time spent making decisions together. These changes were considered to be losses by the well spouses and it impacted the way they navigated roles within their households.

I miss someone to have a conversation with. I miss someone to talk to about issues and I do this with Oscar but it is out of a spirit of respect and acknowledgement, but not because…like to discuss issues going on with Owen. For example, Owen made a Face Book account last night, and I didn’t know about it until I came home from work and then he lied about and I said, “Owen, I’m not an idiot, it’s right here I see it!” and he said, “No I didn’t, I don’t know what happened!” He’s crying, “Mommy you never believe me!”, and I’m saying, “We’ll talk about it in the morning.” So I come downstairs and I would like to be able to have a conversation with somebody about what our son just did and I would like to be able to have conversation with Oscar about this. (Olive)

For me the biggest heart break was…well, when he came here in 2005, I was back home so we corresponded through letters and whatever because in those days we
didn’t have email. He wrote me these absolutely beautiful letters; he would express himself so well. He really had a way with words in the way he wrote. I was supposed to be the writer but I thought he was far better suited than I was, but now he cannot write a sentence without grammatical errors and spelling errors, and of course the hand writing is a mess because of the hand movement. He doesn’t recognize the mistakes if he writes them, it seems that he can’t tell that there’s a mistake. So that part is really hard, being able to accept that is really hard. I used to cry every time I saw his old hand writing in the house. The language skills too. For me, it was a huge loss, to see him lose so much. It was a huge huge loss. It is like that more for me because he can’t perceive and doesn’t see himself; he didn’t have to look at himself (recovering) as I did. (Inga)

**Roles and loss.** Loss was also discussed in a larger context such as how it relates to roles within the family, for example loss of the role of husband or wife. Many spouses indicated that they felt they had lost their spouse to some degree. They also described a process of trying to return to the “normal” ways of life that occurred prior to the brain injury.

I miss him being in control of things, like him leading the way. It’s kind of like he tries and I try to let him with little hints, but, you know sometimes you just want that husband there to do everything, not physically do everything but be the…you have to mind him. (Lisa)

We try to keep everything as normal as possible. That’s what I said to Dr. Harmony, we do everything as normal as possible. If we go out for dinner, he looks through the
menu and he orders his food, just like we would have because that’s the only way he is going to get better. (Heather)

Well, we just had father’s day, he was the host, he was the let’s do this and he would put on the fanciest spread and I would say can we keep it simpler and he would want to put on the biggest spread and be the big host. Now he isn’t able to do that. I try to keep things just the same, so we still host the big BBQ but he isn’t the host, I’m taking it all on. (Anne)

**Role reversal and feelings of loss.** The loss of a spouse’s role as decision maker, parent or otherwise resulted in a change in role for the well spouse as they naturally would have to take on the roles that could no longer be managed by the brain injured spouse. Some of the female participants focused on their spouse’s inability to drive and how that changed the dynamic when they go out socializing together as a couple. These women talked about how they did not want to be the driver and that they felt forced into this role. They discussed how having their partner in the role of driver at social events was important to them and that taking on this role was not a welcome transition.

We have friends in a town a ways away, when we are coming home from visiting them, I enjoy the visit because they treat Al the way they always have…but when I drive home I always think back to how it used to be him driving home and this isn’t fair, it’s me. I don’t like how my life has changed. (Anne)

Here, the participant is reflecting on a role that was previously her husband’s and now she has to take it on. This type of role reversal may be difficult for someone as it is the source of
change, many couples may hold on to the schema, that one person in the relationship should do all of the driving, many couples may operate within this schema. Thus a change to such an ingrained idea may cause stress, disappointment and as in this case unhappiness. Some women were not comfortable with driving in general and indicated that they were unhappy with this role reversal:

I miss sitting in the passenger seat of the car, I don’t like to drive, I drive because I have to. (Elaine)

Yes, I always had a real phobia with driving, so it’s been a slow road for me with this transition. I had started driving before he had the stroke, thank god. But I used to do only…I had my boundaries very close around me, because anything new would phase me. I would get so disoriented just out of panic. I hated going in to a new place and I would always worry about going in because what would be the way out? All those little things that I hated doing. Everyone is in such a hurry, you look in your review mirror and you see them behind you, I’m very…I don’t know what. With someone looking over your shoulder like that just waiting for you to get out of their way. If you’re not completely familiar…for multi tasking at high speeds…I don’t really want to go on the highway…so that gets my family going, “mom take the highway, I don’t want to sit here”. (Inga)

Other’s reflected on the loss of their spouse being the “head of the household” and the subsequent difficulty they experienced in assuming that role. The roles are swapped and thus can be considered to be reversed:
In the beginning it was very difficult. Then there was a time where I realized I was in charge and it was good because we didn’t have to buy computers we could buy towels and sheets and pillows, but that became tiresome. I would give all the responsibilities back if I could. There was a little bit of a power thing where I went hey (this is good) but I grew tired of that. Everything is left to me and I don’t want it. (Elaine)

It’s sometimes…unfortunately my husband is in the position where he feels like he doesn’t count or his opinion doesn’t count, that I take all the decisions anyway, so you know. The power scales have completely turned around. Because he’s not able to do things anymore or he’s not able to think logically through things sometimes, I kind of override what he would like to do and decide what’s best. For me that’s a struggle because I don’t want it to be like that. I don’t like the inequality and more importantly I want a husband who is in a sense someone I can look up to or rely upon. Well it’s completely different now. So I want to help him to that basic end, and in the meantime it’s hard. (Inga)

Well, I was never the boss, and I was never in charge of a lot of things. You know if Luke said we were going on vacation, then we were going on vacation, if Luke said…although I was independent myself, he was sort of running the show. Then after the accident, I had to do everything, and I didn’t know how to do everything, you know, all of the banking and the payments, and it’s really hard. (Lisa)
The men had a similar perspective on taking on the larger role of governing and managing the household:

With Francesca it still feels like we are close to each other but when there is a decision to make she always throws it back to me and says “You’re the boss” and I say, “No I’m not”, but she used to make all of the decisions and I would say “Whatever you want to do let’s do,” I wasn’t that picky. But now it’s all in my court and she asks me to make that final decision. So what I kind of do, whether it’s right or wrong, is I will bring the kids into it. I just don’t feel at times that I want to make it. (How do you feel about the position that you are in, taking care of everything?) I would say that I feel like I am too much in control and I don’t want to be in control. I want to just, sometimes I just want to let the kids take over, but they are still young and they have to grow up to that stage, and take that responsibility. (Frank)

Before we used to share the cooking now I do 90%, same as cleaning. She still cleans a bit if I leave her a plan but she does it as quick as possible so she can get back to watching TV. So quite often I have to do it over. She does the laundry, other than that… (How do you perceive your role within the family?) Well I, if there’s anything serious, the kids will ask me. Well I’ve told them, if your mother says yes it doesn’t count because they can con her. It’s more like, well not quite like a single parent but she’s not really up to being a parent. She’s not really…well you can talk her into anything. (Kyle)

The spouses experienced feelings of loss continuously throughout the various stages in their spouse’s illness. Depending on the dynamics of a marriage, the spouse’s role within
the marriage may have changed from being a partner or from being a secondary decision maker to being in control of decisions in the marriage. The new role of being in control of making all decisions can be a difficult transition for a spouse and can create a sense of needing to parent their spouse while wanting the typical husband/wife dynamic.

**Feelings of loss related to sexual intimacy.** Many of the spouses introduced the topic of loss related to sexual intimacy. When this topic was discussed by many of the participants they were curious to know if the other participants were experiencing the same problem suggesting that this is a topic that is not often addressed. One spouse even reported that she had never discussed this issue with anyone else before.

I mean, I think you will talk to other people about their experiences and I find even sex is different. We don’t even talk about that much in the support group and that’s too bad. (female participant)

I miss sex, yah that used to be very difficult for me. I’ve never talked to anybody about this. I don’t even know if he could have sex. (female participant)

I mean we are still really close, he tells me every day I love you and thanks for sticking with me, and I tell him every day I love you, and that’s it. That’s it… (Laughs), that’s it… you know he doesn’t try to hold your hand or kiss you good night that part of him is all gone. (female participant)

Sexual intimacy is often a difficult topic for any person to discuss with their partner and more so with friends. Thus these spouses find themselves experiencing grief and loss with little support around this issue. They report having difficulty discussing the problem
with their brain injured spouses because they do not want to burden their spouse with worry or because the information is often forgotten before they have a chance to work through it. This problem creates a role transition for the well spouse because they become the primary initiator of intimacy. This role may be difficult for those spouses who were not familiar with this role before and would require a change in self evaluation.

(What have been your biggest struggles?) Well we’ve had and still have sexual problems… (Is that something you are able to talk about with him?) No…we talk about it, we talk about it, probably not enough but we do talk about it. (So there are changes related to the brain injury?) Yes, yes…so we haven’t had sex in many years. We didn’t even talk about this ourselves; we just avoided it until recently… But that’s really a…who do you want to talk to about that? I don’t know if he would feel as comfortable…but he and I don’t talk about it enough. (female participant)

They (our spouses) don’t remember the day before so they’re not as sure about themselves so it (sex) disappears. That (sex) is something that keeps a relationship on a partnership level. It’s changed it. (So do you have to take the initiative there, how has it changed the dynamic?) Yes, and in order to keep it that way you have to take the initiative because they’re not sure if it (sex) happened the night before and if it hasn’t happened in this long, they don’t know if it happened at this time of day or in this way or how you like it and they don’t want to make a mistake, so they don’t. (Is he able to communicate with you about sex?) It never comes up unless I bring it up. (Is that a change?) Yes, that’s a change. That’s a problem. Now we’re still very intimate in that if he is sitting on the couch I will climb on his chair and lay on his lap
and the kids will come in and go ‘oh brother’!...The intimacy has changed on all those levels. (female participant)

(What do you miss?) I said he’s a different person and I said I love who he is now but I gotta tell ya, that the one thing I really do miss in our relationship, is our sexual relationship. You learn to live, you learn to deal. But I tell you if we could just bump that up a notch, I think that we….a little bit of initiation. I don’t want to sound sarcastic, but you know, once a year would be good (laughs). I’m sorry that’s so bad, but it’s just not there. You know, you do the planning and you do the groceries, the arrangements, the schedule, constant … constant, I would love for him to once, just once come over and sweep me off my feet. …but, I’ve had to teach him how to do it all over again…He has his cookbook and his tools to help but where is the tool or the cookbook of the additional spice in life (sex) so to speak? (female participant)

Some spouses chose not to engage in sexual relations with their spouse because it felt uncomfortable. They describe an uncomfortable power dynamic that develops after the onset of the brain injury, and this change is extremely difficult for the well spouses to reconcile on an emotional level. Thus leaving some spouses in a situation where they felt it was inappropriate to engage in sexual intimacy with their spouse. On the change in “connection” with their spouse:

The relationship has changed so much and we have been together for so many years, the idea of having sex with my husband creeps me out, I couldn’t do it. I wouldn’t want to creep him out or scare him; I think it’s the innocence about him. I really am
ok with it. In the beginning we talked about it, we laughed about it…I don’t even care anymore. Really, I think I’m ok with that. It is a loss. (female participant)

(How does her memory problem impact your intimacy, your level of connection with her?) Well obviously that’s affected, for sure. Because she’s not thinking about the future or long term, so you have to come right down to that minute too. So that’s different for sure. Her thoughts are not always right; they are distorted so that intimacy connection isn’t there for me. So the connection or intimacy is not always there for me but I make sure it is there for her…I’m always hugging her and kissing her etc., I let her know I love her…I talk to her about stuff, you know for her, to keep her happy too. (male participant)

(Is it that sex would be something that you are comfortable doing with him, or have your thoughts about it changed?) But he’s changed so I’m not quite…so it feels kind of weird. I think we had a bit of sexual contact, maybe about a year in to the injury and it just felt weird for me because he was disoriented, he wasn’t sort of understanding, he wasn’t himself…It would be like taking on a whole other energetic partner sexually, that isn’t, umm…and he’s not able to meet me in that same place like with that same knowledge, and that same solid grounding in self, sexually. (Can you relate that to the dynamic change in your relationship?) Sure, yah, I mean he’s not…confronting me…I mean that in a positive way. He’s my partner, I have a partner, but really he’s not my partner… (You mean his self propulsion or his independent thinking or…?)… It’s interesting the sexual attraction piece. If we are
heterosexual, what kind of men are we attracted to? I wouldn’t be typically attracted to somebody with his energy right now, to somebody with that energy right? Somebody else might be but not me…That’s where the sexual relationship, I mean yah it is about power and feeling empowered, and him feeling empowered. His libido, his sexual power, his empowerment is not there anymore. (female participant)

Changes in sexual intimacy or a lack of sexual intimacy is experienced as a loss by the well spouses. Also, changes in sexual intimacy complicated the roles in the marital dynamic thrusting the well spouse into role transitions that appeared to involve feelings of ambiguity, conflict, or even resentment. Some spouses however, reported that they were able to reconcile and accept this change in the marital dynamic. Overall feelings of loss were appeared to be enmeshed with the process of taking on and navigating new roles.

On the whole, there were issues that the well spouses reported experiencing throughout the process of caregiving that initiated alongside the illness/injury onset. These issues included: financial concerns, emotional health, physical health, and feelings and experiences of loss. There were also many issues and changes for these families that appeared to develop at certain points in a trajectory of caregiving. These points were divided into three phases of caregiving and are described in the subsequent chapters.
As the initial transition into the caregiving role in the embryonic phase unfolded, the spouses found themselves in a very fast-paced environment as many medical and healthcare decisions were being made that required the spouses’ understanding or input. In fact, the process of caregiving appeared to be initiated by being thrown into the role of caregiver. These well spouses were developing as a caregiver and at the same time they were learning new skills related to brain injury. Overall, the Embryonic Caregiver Phase was a transition where the spouse was learning how to be a caregiver. At that time they were becoming a specialist about their partner’s illness, symptoms, and treatment.

This was a very stressful time for the spouses as everything they were experiencing was new and unknown, and these feelings were compounded by their grave concerns about their partner’s potential to survive. They were worrying about their spouse, their children, and family dynamics. Some may have been worried about the things that were immediately put on hold such as the maintenance of their household, their careers, and family schedules. The Embryonic Caregiving Phase also included learning about the transition from acute care services to chronic care services. Spouses were required to learn about rehabilitation hospitals and rehabilitation treatment. For many the most significant transition occurred when the brain injured spouses returned home. At this point in the brain injured person’s recovery, the caregiving spouses had to navigate many issues that developed at home such as safety concerns related to memory problems, behavioural and personality changes, mood regulation changes, in-home rehabilitation/treatment needs, and changes to family dynamics.
Small Stories: Emerging Schemes in the Embryonic Caregiving Phase

Each of the three phases of caregiving include characters, plots, and settings involved in three smaller story areas. Stressors, feelings and supports are the three smaller story areas that will be discussed in each of the phases of the trajectory. During the Embryonic Phase, the spouses were required to navigate acute care services within the healthcare system. They began to develop new skills (or honed already acquired skills) in the areas of healthcare advocacy and managing their homes/lives while being a caregiver. They were learning about brain injury, hospital based services, and how to access information pertinent to their situation. All the while, they experienced feelings of grief, shock, and uncertainty.

Small story one: Stressors. The initial phase is being referred to here as the Embryonic Phase, to signify the beginning of an emerging role. Many stressors become evident to the caregivers as they encounter the initial health concerns for their spouse and the subsequent daily struggles to address those health concerns. The stressors identified encroach on all aspects of the well spouses’ lives.

Difficulties in care access in the acute healthcare system. Some participants struggled with accessing appropriate care in the initial phases. They found that doctors had difficulty diagnosing the medical problem and subsequently providing the appropriate treatment. The negative experiences with the acute healthcare system were further affected by problems in communication with the medical team, acquiring information about illness and treatments, and poor advocating on behalf of professionals within the medical system, mistakes, and ill equipped hospital units.
I thought the care at Jelly Hospital was less than stellar. (Why, what didn’t you like about it?) The nurses were wonderful, they talked to me they were very helpful. I never was able to find a doctor. I came at all different hours because I was told they were coming at this time or that time. I finally had to go to the Ombudsman to get the doctors to tell me what was happening. The doctors did communicate with the nurses and the nurses communicated with me, but I wanted to speak to a doctor because I knew nothing about brain injury at the time and he was unconscious…In hind sight, ideally what I would have liked was somebody to advocate for him, and unemotionally…because I find that most spouses, male or female, get very emotional…Ideally there should be more than a patient advocate; there should be someone who tells you who to talk to about what in hospitals. (Janet)

When they put him in the ward, that was a bad scene, he fell out of bed twice. I’d go down there and he’d be covered in mess. They would say we’ve got one nurse for six patients, so the family should be down here looking after him. I understand that they are busy too, and funding and that…it’s just bullshit. (Gertrude)

So the folks at Osgood Hospital, they were set up for acute care, they weren’t set up for that kind of a brain injury. So he ended up leaving, escaping from the hospital and they ended up losing him. Off he went, walking down the street in his slippers, he was dressed, he wasn’t in a gown…he was waiting for a rehab bed at that point. He was coming home, although he didn’t know he was coming home. He made it…so I only found out because I came home from work and his friend Oleg had gone in to
see him at dinner time and they only told him then. They hadn’t phoned me to tell me
Oscar was missing. So I pulled up and Oleg pulled up and said, “They’ve lost Oscar,”
and so my dad was here with Owen. So Oleg and I were driving to the hospital
looking for Oscar. So we saw him and he was getting close to home. (Olive)

**Lack of information in acute care.** Some participants needed more information
during the acute phase. They lacked knowledge about certain medical issues and due to the
severity of those issues they felt it would be beneficial for more general information to be
available for people who might experience similar situations in the future. Thus, it seemed
that the nature of the embryonic caregiver phase involved operating with a distinct lack of
knowledge about the problems related to their brain injured spouse.

Well I was confused; I didn’t know what was going on. There were three days were
she was kind of in and out, that was bad but I wasn’t given any information about
what was going to happen…you know the consequences of all of that, you know this
clipping happening and whether or not there was going to be memory loss, we
weren’t told any of that. Especially the first four days and that, I was told to go home.
(Frank)

I remember his friends coming out to the waiting area about day 4 or 5 saying, “The
doctors are pretty…it doesn’t look good.” But at the same time, I had a lot of faith in
Oscar’s tenacity so I hadn’t given up hope. I think it was in layers, I don’t think I
realized that he was in a coma and the cardiac arrest and that his brain didn’t work
…I think not fully because it was so surreal. I always thought it would be nice for families to have a very simple explanation about coma about what’s going on, a package. I finally nailed it down, I said, “I want to know what is going on Oscar,” he said, “Well look at him, what can I say, this is where he is at”, and I said, “I don’t know where that is.” So even, something to say, “You’re husband is in a coma and these are the stages of coma.” At home I was researching stuff but it was all… but I had to navigate all of that on my own. (Olive)

(What was it like to navigate the healthcare system?) Yah it was difficult to navigate the healthcare system, because you don’t know where this is going… you know the extent of the injury, the implications for your family life. You don’t know what kind of help you need anyway, what kind of questions to ask. The information just doesn’t get handed out very easily. You know the only information I had about short term memory problems was from the movies “50 first dates, Ground Hog Day, and Memento.” (Bill)

**Learning the role of advocate.** Spouses began advocating from the very beginning of the injury onset, with a significant learning curve involving trial and error. They described this transition as a difficult role to learn because it required assertiveness and knowledge as opposed to being able to sit back and trust the professionals.

I remember saying something there and the doctors saying you have to advocate for him… yah you have to advocate, but the problem is you don’t know how. (Anne)
Their attempts at advocacy were driven by their perceptions of their spouses’ needs and desires, to a lesser extent on factual information. Thus, there were underlying uncertainties associated with the advocate role. Many participants reported acting from a “gut sense” of what was right for their spouse.

The guy who was monitoring his extremities had him on a horrible amount of morphine. Friends were saying he’s going to die if he comes home. So I picked up the phone and called a neurologist whose name I was given and I told him that he’s going to die if I take him home. They took him, they phoned me right back…But even at St. Alex’s hospital, I had to go to the head nurse and request that the same nurse go in every morning because I could see that it was creating confusion for him. And I asked if we could write on the white board where he is and what’s going on. (Anne)

And that’s hard, it’s hard to find people, or somebody…I’m a huge advocate for Nick. I don’t hold anything back. I don’t not tell people things because it might hurt Nick’s feelings; I don’t go out and advertise the fact that this happened but I will say this happened and this is what you can expect from him. If you can do any better than that, than good on you, so this is what you can expect from him. If you push him too much, then you are not going to get anything because he’s exhausted or he doesn’t remember. (Nina)

So I was still trying to be completely there for him, you know I was running interference between the hospital, the doctors, the social workers, trying to move him forward get him to the next stage, the next level of health care that he needed...That
was where we got to the point where he was finished and they wanted you out of there so they could fill the beds. He wasn’t ready to go and we pointed out that one of the beds had sat there empty the whole time he was there, so how can they be telling us there is such a hurry to get out. So we did push a little bit, you know I put up a little bit of a fight and if we didn’t push he would have just been sent to long term care then. So we had to fight to get him that extra six months in rehab which probably still didn’t do him a whole lot of good. I think now even or a year to two years ago, that’s when I think the rehab really would have done him good. (Claire)

Medication monitoring was a significant part of advocating for their spouses. The spouses discussed various difficult scenarios that made them feel uncertain and uncomfortable in the advocate role because they often had to challenge professional staff. After some time, some of the spouses became more comfortable with this role.

So basically because of the Tetrabenazine, he became very emotional depressed, crying all of the time, and that’s not like him. He’s not a mushy type of guy. I would get there and he would just burst into tears and hug you and say, “I’m so happy to see you.” He was so sad. When we had our first family meeting in January, they were very concerned about that behaviour. That’s when we started seeing Dr. Harmony, first it was his resident that was working with Henry. She came in to talk to Henry one day, and all of the questions she was asking him, and I was thinking he’s not suicidal; he’s not going on any more drugs. So I said to her, he’s not going on anymore medication; I don’t want him on anymore medication. I set up the meeting with Dr. Harmony, and the red flags starting coming up for me and I started researching about Tetrabenazine, and there was a lot of this and that and oh, the
crying, the depression, the sadness…and I’m thinking, that’s him. We weren’t in a way seeing it because of the good it had done originally. So the day I went to see Dr. Harmony, I think he was thinking, “I’m going to have to really sell her on weaning him off of this,” and when I got there I said to him, “So you want to take him off the Tetrabenazine?” and he said “Yes” and I said “Ok.” And he kind of went (surprised look). So I said, “Yah, I’ve been reading about it,” and we went from there. He started weaning him off of it and we started to see a difference. (Heather)

Now Jelly Hospital, they would give him Haldol when he got agitated. They didn’t tell me, I was able to look at the report, and I had a friend who was a social worker who was able to tell me what that was. So I had to request that they take him off of that. What they would do is they would give it to him at night because that was when he was most agitated because he was alone…and then he would sleep all day. I wasn’t against them giving him something to relax him, but their timing was bad. They didn’t really think about what they were doing, they just did it. (Janet)

There was night that was just the final straw for me. I think it was the July long weekend and Oscar wanted his brother to come and get him. So Oscar was still back in the 70’s and saying he had to go to school and he wanted his brother to come and get him. He kept telling the nursing staff that he had to go back to school, and I was up at the cottage with my son…So I talked to him and said, “Your brother is in Ogilvy and you are in Orr, so I can come down tomorrow and take you to school if you still want to go.” So he finally agreed, but something else happened after he got
off of the phone, and I think that was the night that they did the chemical restraint. They just gave him some medication. He might have been trying to leave, I don’t know. When I came back I said to the nurse manager that this wasn’t acceptable, the nursing staff had no idea and they didn’t know how to respond to Oscar…He said, “We’ve never had this kind of issue with a patient before.” So I said I was taking him home at night and that I would bring him back during the day for his appointments. He said, “This is inpatient, you can’t be doing that!” I said, “Yes I can, and this is what I’ll do, the bed is covered, you’ll still get your money from the ministry, it’s no big deal, and you’ll have one less person to take care of at night.” (Olive)

A useful strategy was developed. A few spouses developed the strategy of keeping a log in order to manage the daily changes in doctors, medications, and other healthcare providers, and to reduce stress. The log helped these spouses to discuss current and changing medications with doctors and to feel like they have control over the care of the spouse. The log helped them to feel like they were a part of the decision making and an advocate for their spouse’s healthcare. Keeping a log helped these spouses have a more positive healthcare experience, by helping them to be more organized and prepared for medical appointments and conversations during this embryonic caregiver phase.

(So you’ve been journaling?) Yes, for five years. First I had to keep track of what was going on with him, who cared for him that day, what was his medication, who was his doctor, why they give him that, who said he had a problem, what was the nurse who caused the issue, when did they start with this, why did they move him here. I needed to be able to respond to somebody’s questions. I needed to have my answers clear and
precise so that I could move him into the next step or to find out what needed to get done. (Nina)

When he first got transferred to that hospital, I had this list of medications and every time I gave him a pill I had to write down every medication he was given, how many, the time. The nurse there asked me if I was a nurse, I said no, but for the last six months I’ve had to keep track. I wrote everything down, I had this huge file. I took it every time I went to the hospital, it’s huge. (Anne)

I have a little book where I wrote everything down…So I just wrote everything down. That kept me straight. So when we would go somewhere new and they would ask me, I could just flip through and give them the information. I think it was therapy in a way for me. (Heather)

Moving home from the hospital. The spouses discussed many transitions and changes in the process of their journey; one of the first changes after the acute health change and care issues was the transition home. After going through the transitions of recovery in the acute phase of the illness, the brain injured spouses would be discharged home. The initial phases of coming home could be quite an unsettling experience for the well-spouse as they had to start learning about all that was different for their spouse both physically and cognitively.

I couldn’t leave Beverly alone; I couldn’t leave her alone at all. The first few months you think she is going to get better, so you go through that transition. Then once you realize that she may get better but it may take a lot longer, there is that transition.
Then you realize this is it which makes it easier because now you know where it all stands. After a year and a half now you've settled into it, things are a lot better than a year ago, you know what to expect from her and you know everything about her, the illness. I know how to get out of little discrepancies with her now. (Bill)

I guess Henry coming home was a huge transition. Going from hospital to hospital was hard enough, but coming home you realized …I mean… you always appear healthy or better when you are in the hospital because you are not really doing much. You aren’t getting up; if you do you are right back in bed. Then at home, you see everything (that he is capable or not capable of). So that was a huge transition.

(Heather)

Whereas trying to adjust to work and home, and him and paperwork from insurance companies or CPP or learning how to do the taxes, or trying to keep up with things…there’s not one thing I can put my finger on, there’s lots of little things that I could tell you…just a total stressor. (Nina)

**Accessing care in the chronic healthcare system (in the community).** Various role transitions occurred once the brain injured returned home from the hospital. Some of the role changes were overtly discussed and others (to be addressed later in the paper) were insipient and gradual and not necessarily readily identified by the participants. The chronic phase of the health care system left many of the participants feeling let down and invisible; further maintaining their role in the embryonic caregiver phase. During this time, the brain-injured spouse is released from the acute care hospital or rehabilitation hospital and sent home. At
this point, the participants had to rally to find appropriate homecare services and support systems. They began to juggle the role requirements of taking care of all demands of the household including their spouses care. Their supports started to disengage during this time and the participants struggled to learn how manage all of their role demands independently. In struggling to manage, they discovered that there were few services that were appropriate for their brain injured spouses, and, even fewer for themselves and their children. It was difficult to access appropriate and relevant information regarding healthcare for their spouses, and this problem was compounded by the stress of the unfamiliarity of the situation, and their personal losses.

It was like learning a new language. It was a whole new area; I did not know anyone who had had a brain injury, even a stroke. I didn’t know how much work there would be, plus, I had two kids at home and he needed full time care…I will tell you, and I would like this to go in your report, that he had a number of episodes for a few years where he would just faint. Some specialists denied that it’s anything but the support group…many people in the support group said their spouses had that. They called them drop seizures or silent seizures, where they would just drop. I was really worried that he would hit his head and a couple of times he did but he didn’t seem to damage it any worse. When we would go to the hospital, they would never be able to find anything. They did send him to a neurologist who sent him for cat scans and MRI’s that found nothing which is good. (Janet)

I was stressed; I didn’t know what was going on or what was going to happen. I didn’t know to what extent this illness was going to, was it going to get better…you
know…where it was going? You just don’t know and when you think you’ve got it all figured out, it changes. (Bill)

That’s when the whole therapy piece started. At that time I had no idea what was to come or what was going to happen. I had no idea about changes in her memory or thinking or what was going to change in her. From that point we started to see some changes in her, she is a completely different person from the way she was before. (Frank)

*Lack of available services in the chronic healthcare system.* Most of the participants commented on the lack of services in the community for their spouse. This gap in services seriously impacted the participant’s ability to cope and manage their everyday lives. The lack in services available or the lack of easily accessible services created much more work for the spouses because they were then required to spend considerable amounts of time searching for services which was a daunting task given the number of new roles they had taken on during the Embryonic Caregiver phase.

Coping on a daily basis, figuring out what was going to work and what was not going to work. I’m a coordinator by trade so I have to have a lot of structure in my life, this was no different. I had to know where he was and what he was doing at all times. Everything was a struggle until you learned how to deal with it appropriately, until you were accustomed to how it was different… when I first thought I was going to lose him, that was my first call to my girlfriend, and it was just…the internet is just
not the best thing to read, horrifying. But we made it through, and we will continue to. (Nina)

(How did you find out about services?) You know I wasn’t looking for somebody to take care of Beverly or to come to take care of me. I wanted Beverly to get better, or be more functional or more independent, that’s what I was looking for in terms of services. There wasn’t any of that until this place came along. The doctors were all great and supportive down in the big city. I had no idea what to expect or what was available. (Bill)

I did spend lots of time googling stuff on the internet and I would call and get responses like “Oh that program is not for him, try calling…” such and such, bullshit. There are no programs. They’ve got daycare centers for seniors where you drop them off in the morning and pick them up after work. Even if I wanted to pay for that they don’t have that for Gord’s age group… If Gord was 65 or 70 years old, he’d have had a better chance of getting better care. All the programs are all geared to seniors with Alzheimer’s. What about all of these young guys. It seems like from about 35 to 65, there’s something really lacking there. There are no programs and no help. Nothing…just the lack of any programs, the lack of anybody taking an interest in this age group. Even if we had to pay a small fee and the government subsidized part of it…it would make my life a lot easier knowing that he was someplace during the day where he was looked after. It would make it a little easier. The thing that would help
me is better programs for him… and a drug card. But I don’t see that happening.

(Gertrude)

The lack of services caused the spouses to feel isolated in their own communities. Sometimes they lost hope and drive which impacted their ability to navigate their caregiving role.

Like not being sure if Oscar…and the PSW’s and figuring out that system. Trying to get support… and then the right support that was appropriate for Oscar and also respectful of Oscar. A lot of personal support workers…they just didn’t…I know they’re not…you need to pay people better to get quality care. I didn’t have a lot of money to be paying. (Olive)

Sometimes…I feel like it’s too much, too little time, too little resources. Everyone tells me just ask me for help if you need, but…it’s…I think if you have someone living with you who can help it’s different than having to call someone…you don’t what their schedules are and if they’ll really be able to help you. You want to reach out sometimes and ask for help but somehow the situation…it’s not the right time, or you can’t get hold of the right people. So sometimes I end up getting a little overwhelmed. (Inga)

When Luke came home, obviously he wasn’t as well as he is now. I mean he had a diaper; he’d just want you to do everything. I think to this day he doesn’t realize, well he didn’t then…that he had a brain injury and he couldn’t do all of these things that he thought he could do…but he would argue with you. Then he would say that I was
treat him like a baby. So what do you do, and I had to go back to work, and he needed someone twenty-four seven. (Lisa)

*Lack of information predominated the chronic healthcare system.* The participants described their struggles regarding accessing information about brain injury services for their spouses, and information about accessing disability compensation. The participants described various complications to finding adequate information and how this process made their role as caregiver feel more difficult.

*(So what was like navigating the healthcare system?)* Well absolutely horrible because you don’t know who to go to. However, when we were at Langley I met with a woman and she was going to be my contact, I can’t remember her name. She said she would help me through everything, but I never heard from her since. Even for after care, then what do you do? Like we live in Largeville and there was a brain injury group in the next city over and one of the women in it my girlfriend knew quite well, and her husband had a brain injury, he had an aneurysm. So she had already gone through all of this. So it was just what somebody told you, there was nothing written down to tell you where to go; no one that we could call. (Lisa)

The fact is the literature didn’t really capture it…and people will tell you what they think but they don’t really know. I don’t know how much medical knowledge has improved about brain injury in the past 20 years. So some people said I would see improvement others said maybe in six months to a year but I didn’t really know what that meant. Even now, I’m still occasionally surprised and I still collect whatever information I can from newspapers and magazines. Occasionally if I run across a
study I will read it but I still think there is very little information available.

(Information about services or what to expect, what kind of Information were you looking for?) The services yes, there wasn’t information readily available to people about services. After two or three or five years I was still discovering what was available in the community…That was something I didn’t know about until someone told me that I could apply for her to have a disability pension. I think that was the part about being permanently disabled, you know she is basically that way but I wouldn’t have known at that time and so he helped with that part. (Doug)

What I would find more useful, is to have a 1-800 number, someone I can call up and ask questions. I think I would find it more useful to have a number I could call when I have a question or to ask for advice or information about particular situations that you have to face… I was thinking that it would be really nice for families to have a life coach kind of thing, somebody to stand by them. (Inga)

Small story two: Feelings. In the Embryonic Caregiver Phase the spouses go through a number of role transitions. For many, the initial role transition was becoming a caregiver. As outlined in the examples above, becoming a caregiver however, involves taking on many new roles. These new roles may have involved, coordinating healthcare, navigating medications, moderating family dynamics, becoming a specialist about services, being a care provider (bathing, toileting, feeding, dressing), being a rehabilitation therapist (teaching skills of eating, talking, writing). Other new roles in the household may have also been taken on that were previously held by the brain injured spouse. Because of the numerous role transitions, the transition into new roles was not always seamless and the well spouse
experienced feelings such as anxiety, stress, uncertainty and loss that interfered with the ease of their progression into new roles.

**Feelings of uncertainty.** The best descriptor for the embryonic caregiver role is that it was a time of uncertainty because the participants were not initially actively aware that they had entered into a caregiver role and they were distracted by the daunting tasks required of them. The participants reported that there were many “unknowns” that contributed to their feelings of uncertainty. For example, they were feeling uncertain about the illness/accident implications, medical procedures, healthcare institution processes, all outcomes and immediate and long term future. Understandably, this is a very unsettling time. On the uncertainty during the first trip to the hospital and initial interactions with medical professionals:

They did a CT on him and I was waiting back in the room for him, and they had indicated that they would come out and let us know what was going on. I was walking through the hallway when one of the doctors came up and asked me if I was ok with the information. I said, “Ok, what information is that? He said, “I’m sorry, nobody explained to you that your husband has had a brain aneurysm and a brain injury”. So I said, “No I didn’t realize that,” and I told Nicole and mom, and then we had to call his brother…Doctor Nite talked to us quite a bit about what might happen and how there wouldn’t be a timeline for what would get better or if it would get better. Everybody’s different, it could be ten years before they come back, it could be never. So …they won’t tell you in two years he’ll be fine because if he isn’t in two years you’ll be back saying, “No he’s not.” (Nina)
Even in the hospital, the doctors, they’re funny…they don’t tell you the whole story. There was one young neurosurgeon in there, and he was the only guy that told me the truth. Because Gord had been in the hospital for awhile, I thought it was the drugs, they never said that his memory was gone, no one ever said that to me. Until one day, and this new doctor was in there and I asked, “How long is this going to go on for?” and he said, “The rest of his life.” That just threw me for a loop; I remember saying “What??!!” (Gertrude)

The ambulance attendant said, “Just take your time coming to the hospital,” and I remember thinking, well that’s not good. So then my brother took me. So then they took Henry out and it was at least an hour and a half until I saw him again. When I got to the hospital, they gave us a room to wait in. My brother and I waited there, it seemed like forever, but it was probably 45 minutes, and then they let me in to see him. (Was he stable by then?) No, he had several episodes, which they called a cardiac storm or an electrical storm, where his heart stopped a couple more times and they had to revive him…There are a lot of unknowns. I think heart wise and health wise things were going good, as far as we knew...Yah there are a lot of unknowns. (Heather)

This embryonic caregiver time involves an extensive amount of role uncertainty. The well spouses indicated they did not know what their role was, or how to respond, or what to do. The reported that becoming a caregiver that was a process that was thrust upon them and they had to learn as new events transpired. Some were able to call on previous experiences (such as being assertive or knowing how to find information) in general and some called on
specific previous experiences (previous experience with healthcare navigation or knowledge of brain injury). Regardless of previous experiences, all of the spouses reported feeling like they were participating in a situation they knew little about.

*(So how did you navigate that, if you didn’t know how?)* I think you are pretty bitchy. You get pretty bitchy. You know you get there and they say take this report, well you get to the hospital and if you haven’t given them the report at the check in they can’t send it somewhere else. And you think what do you mean? They should have a sign at the check-in saying if you need reports sent somewhere else then you need to submit the report on check-in? I’m not one to take things lying down, and I complain, I complain up the… if you didn’t, I don’t know how things would get changed. If you were a person going through that alone, I don’t know what you would have done…Then finally the last time... he was at another hospital and they wanted to send him home with no more tests booked, saying I need to get him a physiotherapist and a walker. (Anne)

The lack of knowledge about the types of health problems their partners were experiencing lead to further unknowns and feelings of uncertainty. Many of the spouses initially assumed that their partners would return to “normal” both cognitively and functionally. Many months or years into the illness, they eventually learned that the recoveries would be limited. Here there was ambiguity about how long the caregiver role would last; at that point, the participants were expecting things to return to normal.

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(Have there been any transitions or changes that stand out for you?) I guess coming to the realization that this might be the extent of her recovery. Earlier on it was “We might get our old Mary back,” and I think the transition has been, “This is the lifestyle we are going to have, this is Mary for the rest of her life.” I think that is likely the case. So it’s being able to adjust to the fact that what we’ve been doing for the last year and half after the acute stages…that that’s how it’s going to be. (Mike)

When he started to wake up, I was imagining, oh he’s going to wake up and he’s going to be fine. He had a lot of trouble recognizing people, he had no idea where he was, even if you told him he was in a hospital, you know, five seconds later he wouldn’t remember. At one point, he thought he had gone crazy, he said to me “I must be in a mental institution, that’s what has happened to me.” …It was virtually impossible (to work); because I went into this thinking that he would be fine in a few weeks. Especially when he came out of the coma, because you think of the movies and you say well he’s out of the coma things are going to be fine, it will take him a few weeks to recover and he’ll be fine. I had no knowledge of brain injury other than my mother died of a brain tumor and I saw what the brain tumor did to her. (Claire)

If we are aware at the beginning of what we are going to expect, like having an understanding of the challenges we are going to go through, rather than when the person comes home you are realizing the challenges like therapy, like why is there therapy? Is it going to get better…you know we were learning as we went along.

When someone is in the hospital and they’ve had such an injury, to know this is what
you can expect and this person is not going to be the person that you knew, it’s going
to be changed…you’ll see it as you go. That’s information, that could be gathered as
you go for research you know, the stages. You know, initially I thought, she has a
bleed, they’ll clamp it, it’s done, and eventually she’ll go back to work. Well that’s
not going to happen, life is completely different. (Frank)

**Feeling prepared.** As would be expected, all of the spouses discussed being affected
by stress and anxiety. Not feeling prepared for the injury onset increased feelings of stress
and anxiety. The well spouses discussed worrying about lacking the resources to address the
emerging stressors because they did not feel prepared.

*(Did you feel prepared for this event in your life?)* Oh God no. You don’t prepare. It’s
kind of like I’ve never done this, but it must be a like a guy training to go into battle,
was I trained for this… well I had relationships and communication skills and
understanding but are you really ready? No. It’s like one surprise to the next. When
we went in it was Mary’s got a headache, stress. Almost laise faire, we’ll be back to
normal. Thirty six hours later I was sitting in Meritville wondering if I would ever see
my wife again. Nothing prepares you for that, you get into coping mode. Early on I
had a lot of support from family and friends in the very acute phase. (Mike)

*(How were you feeling during all of that?)* I think I was just in shock. I couldn’t
believe it was happening. We always had a joke about hockey, Henry would say,
“Hockey for the heart.” Henry played junior hockey and stuff, obviously he wanted to
be in the NHL and that never materialized and he was devastated about that for a long
time, but he always played hockey. You know at 44, to still play hockey twice a
week. He was always focused on his health, he was a healthy guy, and sometimes
he’d get a call asking him to play one night and he’d go, “Heath…come on
Heath”…I’m like, “Yah I know, hockey for the heart!” My girlfriend said to me,
“You two have always had the fear of…” and I said, “Yah a regular old, I don’t feel
well, run of the mill heart attack…we didn’t need the big Kahuna.” I guess we never
thought it would happen. He was so conscious because of his family history, he did
everything to make it not happen, and then for it to happen, I mean I used to joke with
him about having to get knee and hip transplants from all of that hockey because he
does have bad knees. Those were the kinds of things we worried about would happen.
Now I have to think….the defibrillator is always there, but, he’s doing ok now, but in
10 years will he be ok, in 20 years will he be doing ok. At 44, I faced that I might
have been a widow, and now it’s always going to be there, that it can be close.
(Heather)

(Was it stressful?) Yes, extremely stressful. At first, he was in Langley hospital and I
was living in Landville. For the few weeks it was ok, they had a little room I could
stay in at the hospital some nights, and then they gave me discounts for a hotel so I
would stay there and just walk to the hospital. So that was good but he was
unconscious. So it was stressful but he wasn’t awake, he didn’t know what was going
on. (Lisa)
Some of the spouses indicated that they had experience with being in the caregiver role and that this helped to reduce the stressfulness of their situations. Having been a caregiver or helper in the past seemed to help some of the spouses feel more prepared and thus they were better able to cope.

(Do you think having had that experience before, helped you manage things with Al? How did you feel it impacted your ability to manage your situation?) Obviously it helped me because people know if they have a crisis, you call Anne. If something is going wrong people know to call Anne. If it needs to be done, I’m a doer, it doesn’t matter what needs to be done, I’m your girl. So yah it helped me. I guess it’s my personality. (Anne)

(How prepared do you think you were for this to happen in your life?) Hard to say…nobody is ever going to be prepared for this to happen, ever. Was I one of the more fortunate people or unfortunate people to have this happen twice in their life? I knew what to expect when he woke up the next morning, and when he started turning black and blue all over, or when he had wires coming out of his head. That I was all prepared for. If you asked me that 16 years ago I would have said hell no, not prepared at all, didn’t expect that. But was able to cope with it better (this time) but I also had the support of Nicole [daughter]. Whether she knew it or not, she was strong. She is built from good stuff! My mom’s a strong person, I’m a strong person, she’s a strong person; an amazing young lady. I wasn’t prepared; nobody would be prepared for this. No more than I would be prepared if, god forbid, it didn’t come out to this wonderful place in life. It would have been a whole other way of life to get used to.
I’m sure I would have done so, but I’m glad it’s the life that I get to share with him. 

(Nina)

**Feelings of loss initiated the grieving process.** As discussed in Chapter 4, feelings of loss were experienced throughout the caregiver trajectory. In this phase, the initial feelings of loss related to the health changes of the brain injured spouse became initiated the process of grieving. Unfortunately, the spouses had very little time to focus on their grief as they had many aspects of their crisis situation to address.

Well, I don’t really have a wife anymore. I got another kid, you know. It’s a big loss, it’s like, for awhile there she thought I was her father and she would ask me, “where’s your wife?” and I would say “you’re my wife” and she would say, “No I’m not”. Immediately after, she didn’t know us, didn’t know the kids. (Kyle)

So there was a time of grieving that I had, but those first few weeks I grieved, there was a lot of grieving… but at the same time there was so much to be done I had no time to grieve. In a way that was good, because I had to keep my mind from going to mush and I had to keep, I had so much at stake I had to keep everything running more or less…For me, it was a huge loss, to see him lose so much. It was a huge huge loss. It is like that more for me because he can’t perceive and doesn’t see himself; he didn’t have to look at himself (recovering) as I did. (Inga)

(To review more data points representing feelings of loss please return to the discussion of loss in Chapter 4.)
**Small story three: Supports.** The Embryonic phase was initiated with a crisis and for many of the spouses, their friends and family responded with support. They were receptive to the supports offered from friends and family to help them through this crisis phase. Support was also received from various treatment professionals in the acute care system.

**Professional supports.** Most spouses recounted that access to healthcare services at the acute phase (illness/injury onset) was easily achievable and that they were happy with emergency services and emergency health professionals. They found various supports within this system. Many of the participants found professional individuals who were helpful however, the instances of finding helpful people often appeared to happen by chance:

> Again I did all of the paper work which was quite extensive, luckily her physician was willing to help and to sign the documents even though they were new to us because we were in between physicians at the time…but this one I got the sense he had seen this a few times because he was the one who said we should fill out the forms and this is what you have to do and this is what you have to say on the form because if you don’t give the correct answer you don’t get the money. (Doug)

> I have to say that, as much as I didn’t want him at that hospital because I felt there were incompetency’s there, well there weren’t. They did an amazing job for Carl, right from the doctor that took care of him in emergency. That’s why I say sometimes it was divine intervention, because what were the chances of getting an internal medicine specialist at emergency at 1pm at a small community hospital. So from him to the ICU team, the nurses were unbelievably caring. (Claire)
The ambulance guy Oli…once Oscar was taken care of at the hospital…Oli was saying to me that his father, the reason he became an EMS worker, because his father, when he was a little boy had some sort of life threatening event and his father was saved by an ambulance driver, so that’s why he became that. I think our situation touched Oli in a certain way and he came in a couple days later, he came in a few times while Oscar was in intensive care, he just wanted to find out how he was doing, so that was nice. That was a whole other relationship that came from that. (Olive)

**Family and close friends were needed for support.** During the Embryonic phase the well spouses were very busy spending their time initially at hospitals and later at rehabilitation appointments. They needed the support of family and friends to help them with caring for their children and managing their households while they were in the crisis phase of the illness or injury onset. Many friends and family members offered their help and support during this phase.

After he finished his treatment…I had a friend come down from out of town and sit with me while I tried to work out how I was going to make this work. You know I had to go back to work; he had to go to treatment. How were we going to get him there? The volunteer drivers don’t take him into the hospital, just to the door…Finally CCAC set up a cab for me, as long as a family member went. So my mother went, my daughters went, I went, our friends went. We all took shifts. (Anne)
We had a lot of people on our side, and, I have to say we have the best group of friends going. One of Nick’s best friends is familiar with critical injury, who also had amazing contacts with respect to the Rehab hospital where he did his rehabilitation. So you kind of had the connections and support where you could say “I don’t want to deal with this, here you take care of this, and I can’t do this”, or someone saying “What can I do”. It was great. (Nina)

My sister moved closer to me, she doesn’t have children…they’re very much a part of our life. My sister was an amazing support while Carl was sick; she took time off of work and did shifts with me at the hospital, pretty much every day. His sister has been really good too, she doesn’t live too far and she committed one day a week to take him out too in the beginning. Friends, we are really very fortunate. Carl’s two very good friends were at the hospital every day. They helped out with the 24 hour watch, they took shifts. Our friends still socialize with us. I’ve worked really hard at that as well, making sure we stay connected with friends. But we are very blessed to have such good friends… A core group of good friends has really helped, and not just to help me do things but just to be there when I say can you meet for coffee this morning. (Claire)

Small story four: Living in the moment emerges as a marker for a transition to a new phase. After the spouse had been home for some time, participants experienced a change in perception. They found that they had become more focused on the present. They found that they could only address the crisis of the day and the family’s needs for that day. They described their situation as living more in the moment or in a state of “suspended
animation”. They also noticed that the brain-injured spouses lived in the moment as they did not seem to think forward to the future nor did they dwell on the past. The participants found this new phenomenon difficult as their previous lifestyle encompassed past, present, and future; with thoughts of future being the driving force for motivation to do certain things in life. They reported that living in the moment causes one to slow down and to completely focus on the family unit; allowing for immersion in new roles and resulting in a much slower and more isolating way to live.

You know like Carl, he’s doing wonderfully and he’s progressed really well…now I understand when I first started the support group and they discussed how they (people with brain injuries) live in the moment, because he’s not really involved. For example, he still has no idea about our finances and what’s happened to us (financially) because of the event. (Claire)

He would always want to know in the past what was coming, so this is a whole other way of him having to be in the world, and it was something he would have been very uncomfortable with in the past. (Olive)

(So your forced to be in the present, dealing with the day all of the time?) Yes, and that’s not fun because most people plan and that’s what allows them to have something to look forward to. I spent all my life planning, you know; when you will buy a house, have kids, when the kids will do this, that kind of thing. I have put some of that stuff back into perspective now. (Anne)
Once the participants fully transitioned through the embryonic caregiver phase they started to feel more competent in their new role as caregiver and they had learned many new skills. For example, they were better able to anticipate some crises easing their efforts to spend more time planning treatments and ways to improve their spouse’s functioning. The spouses were still experiencing problems or crises in caregiving but had a stronger skill set including problem and emotion based coping techniques. This transitional period moves the well spouse to become very focused in the moment because they became very immersed in addressing the unwell spouses needs at home in community while mastering the numerous role changes within the household. When this happened the themes that emerged suggest that the participants moved to an Immersed Caregiver Role and they did not appear to return to the Embryonic phase. At this time the participants and their dependents became completely immersed in managing the participants’ healthcare and rehabilitation needs. The subsequent impact on the caregiver’s feelings and ability to cope is discussed in the following sections.
Overview: Transitioning Into the Immersed Caregiver Phase

The Immersed Caregiving phase emerges after the brain injured spouse has returned home from hospital and a process evolves where the well spouse and family gear and modify all activities toward supporting the brain injured individual. This phase is characterized by feelings associated with caregiver burden because more role transitions emerge and there appears to be less contact with outside social supports once the previously hospitalized spouse is home. In addition, the caregiver spouse also begins to disconnect from supports. In this phase spouses may quit their job, or maintain their job with concessions. Children may be expected to adapt, compensate for, or support the brain injured parent. The findings regarding the three main small stories in this phase (stressors, feelings, supports) are discussed and explained in this chapter.

Small Stories: Emerging and Continued Themes in the Immersed Caregiver Phase

The role transitions discussed throughout this section reveal how the spouses are engaged in a process of becoming an Immersed Caregiver, transitioning from the Embryonic Caregiver phase. After the injury, the spouses endure many changes in lifestyle and routines. As the spouses became engaged in the immersed caregiver phase of caregiving, new role transitions emerged once again, and as in the embryonic caregiver phase, these transitions involved complicated feelings and underlying moderators. For example, the role of caregiver itself begins to change in meaning as the well spouse begins to become weary of their
partner’s prolonged condition and they begin to search for avenues for greater progress or recovery.

**Small story one: Stressors in the Immersed Caregiver phase.** As the well spouses initiate the process of navigating the brain injured spouse’s care at home they become heavily immersed in the roles that are entirely focused on providing for the brain injured spouse and this immersion is the ultimate stressor. This stressor causes feelings of emotional and physical exhaustion which subsequently results in feelings of burden.

**Changes to patterns and routines are stressors.** In many situations, the caregivers appeared to attempt to return to old routines. This was often impossible at this point in the caregiving trajectory for many reasons. Consequently, the well spouses were forced to accept this impossibility in order to adapt and develop new routines. Developing new routines lead to the conscious “realization” that roles were transitioning. Furthermore, changes in routines lead the participants to acknowledge that they were living in the moment; and as discussed earlier in the results this was a transitional phase into the Immersed Caregiver role:

> So there is tired on every different level. And then there is just tired. I am tired of being in suspended animation, where you are living in the here (the present) like he does. Tired of the situation. Tired on every level possible. (Anne)

*(How long did it take to get back to your routine?)* I think over a year. The first year, we used to have somebody at the house, all the time. We hired a caregiver for the first year and a half. I took some time off work but not a lot. I actually moved my office home, and I could actually get up, we started at 7am, so I could get everybody out on
the road and be home before the kids went to school. The kids were in high school then…so I would go to work, do what I had to do and get home before the kids left. So I made sure the kids got to school. (Kyle)

It’s just the…you know, we had a busy life. We would have a conversation, where I would say, “Are you going to meet us at soccer tonight?”… If he was going to be working late, he would meet us at the game, or he would say no, “You pick her up because I’m going to drop her here.” You know sending messages to each other on the fly, or he would say, “You know you tell me who to pick up at what time.” It was busy, we both worked, we have two kids, and two puppies…and we just had a busy life. It was like all of a sudden we got hit by a bus. (Heather)

**Leaving spouse home alone was a problem and a stressor.** Many of the participants discussed the difficulty of leaving their spouses at home alone. Discomfort with leaving brain injured spouses home alone contributed to role overload and propelled the caregiver into the immersed caregiver role as their focus throughout their day was solely on their partner’s safety and care needs. Some spouses simply stayed home with their spouse, others who did not stay home, worries constantly and were consumed with coordinating alternate sources of homecare for their partner. This situation underscored the need for more health care support during the chronic phase of recovery.

Last year I stopped playing baseball, I stopped playing hockey because I just couldn’t leave her, we couldn’t get help in either. I didn’t want to leave her with strangers so I never did. So I realized it was going to be me and her. (Bill)
Some people just can’t understand which is fine, because I wouldn’t leave Edward, not for more than a few hours tops. I don’t know if that’s just me, but I feel like he would try to do too much, like if he would decide to fry himself up a steak or something or burn the house down, I don’t know I just wouldn’t feel good. It wouldn’t matter what he’s doing it’s what I think he’s doing…Coming September this is a whole new thing for me because my son is going away. When he lived downtown for school, I had CCAC come in once a week so I could go out for dinner, but I cut that off when my son came back. Now he is going out of town. So I am having someone come in to assess Edward for cooking and being alone in the house to see what they think, because I don’t know if it’s just me worrying. So September will be an adjustment. Maybe they can make me feel better. My biggest worry is that he goes to the washroom and forgets to put his breaks on. I need to hear that he can do this and he will be ok. (Elaine)

(When Al returned home from rehab, what was it like, was it always ok to leave him alone?) Initially there were huge issues and I had friends who would come and sit with him. We just slowly backed it off. People checked on him, and now we make phone calls. I work just around the corner and I come home for lunch. I don’t call home unless there is something I’ve forgotten and he doesn’t call me. I know other people in the group spend a lot of time on the phone micro managing, but he is pretty independent. We put things in his palm pilot together, so he sees that and he sees the kids, if he sees the kitchen needs doing, he will do that which is his thing. When I come home, he will tell me what he’s done, sometimes I’ll come home and be
concerned about what he’s done. Last week he took the storm window out for my
daughter because he heard us talking about it and realized it was something that
needed doing. That’s a scary thought because it involves a ladder. He doesn’t usually
not use good judgment but when you are used to being able to move a mountain, how
do you sit there and do nothing. This involved getting an extension ladder off a shed.
Usually he helps me and we do it together. (Anne)

Changes in relationships with friends and family are frequent stressors in this

phase. As the participants transitioned into becoming more immersed in the caregiver role;
they became more aware of a number of changes in their interpersonal relationships. They
discussed many changes in interpersonal relationships with family and friends. They
discovered there were changes in their spouses’ relationships, changes to their own
relationships, and changes to their relationships as a couple. These relationship changes
affected coping styles and created additional strain and duress to their daily experiences in
caring for and supporting their spouse. The participants speculated about the reasons why
their relationships changed. They discussed issues with time, uncertainties, others moving
forward and how these issues made it more complicated to navigate interpersonal
relationships:

The real difficult thing though is that they (friends) are able to do so much more than
we can. Whether it be Carl’s challenges with fatigue, or if it’s financial, so that’s
really hard. His one good friend, he’s been a friend since grade 9, well we always said
that we would plan a trip together. Then of course Carl got sick and they said they
would wait and they did. Well recently we went to a seminar about a tour in Cairo
and it looked very good and maybe in a couple of years Carl could handle it because
you would be stationed in one town. So I said ok maybe we can try to do that, which
was about a year ago, and they got back just this past June. So I told her listen, I don’t
want you to pass up an opportunity just because we can’t come…I don’t know if we
can go a year from now, maybe two, I don’t know if we will ever be able to come. So
if you can go, don’t pass up the opportunity. So that was really hard. (Claire)

(Have there been any changes in relationships with friends or family since this
happened?) Yes, well people have to relate to Oscar differently than they used to.
There were some people who were able to make that transition and some people who
aren’t, for whatever reason. (Olive)

(We’ve talked about relationships within your family, what about other relationships,
like with friends and extended family?) A girlfriend she helped in the beginning and
she called everyday and that stopped. Once things settled down, I thought ok, they
don’t want to rescue me and they have their own things, fine, but I don’t want to keep
calling and them not return my phone calls. Then they say it’s not that… “If I don’t
answer call me at this number”, but you’re not sure because you don’t want to be a
burden to anybody, so you just try and keep it light now, and get together when you
can. Their lives have continued in a forward motion, their wants and their goals and
plans are continuing. So they are sometimes doing different things that you can’t do
with them either financially or physically. Yet you don’t want them to be afraid to tell
you that they are doing those things, you want them to feel comfortable to tell you
about their good times. But, they know you’re kind of stuck, and they’re buying the new car or renovating their home and you’re just kind of keeping it. (Anne)

*Changes in the brain injured individual’s pre-existing personal relationships were stressors.* The participants noticed that there were also many changes in interpersonal relationships with family and friends for the brain injured spouses. These changes were very difficult to accept and added stress to their already stressful situations. The participants carried the burden of worrying about these changes:

*(Has there been any changes in any relationships since this happened with Kate?)*

Well she went to college with this group of girls, and they don’t… but they still talk to her but definitely not as much. They used to be this little…you know we’d see them three to four times a year, now once a year. (Kyle)

His brother, I think it just was really hard, and he couldn’t articulate that to me. He couldn’t say, “I’m not comfortable with Oscar” because I wanted him to come and spend a weekend with him in the summer when Oscar first came home, and he said “Oh, I don’t know about that.” He wasn’t able to really…so I make a point of Christmas, Easter, and during the summer phoning his brother, and going and seeing him… One of his good buddies, had made a huge life change, it turns out partly because of what happened to Oscar. He left his wife, and it was just a mess, he started an affair with another woman. Partly because of seeing what happened to Oscar, but we don’t see him anymore, it’s just occasionally. He came to see Oscar on his birthday last April, we had him over. We used to see him every week, Oscar would go with him to band practice with him, and it was too hard for him. (Olive)
(You mentioned some changes in some relationships since this happened, can you tell me more about that?) Friends… a lot of his friends disappeared because he is different. I also think that I might have had a lot to do with some of them because they were smokers and I didn’t allow it anymore. They made indecent comments and as far as I was concerned, ‘stupid’ was not a vocabulary word in our house anymore. Any type of joking around with that sort of stuff I didn’t appreciate. (Nina)

Changes in the couple’s pre-existing relationships with other couples are stressors. Many of the participants discussed changes in relationships they had together with others as a couple. These changes emerged and/or were recognized during the immersed caregiver phase in the trajectory. They reported that these were very difficult and hurtful changes that were quite unexpected. The spouses discussed how these changes stemmed from other’s perceptions and misconceptions of how they were handling the stressors related to the brain injury. Essentially, the spouses felt through the process of taking on and engaging in the caregiver role, they were often misjudged by others. Subsequently, they had to learn how to cope with their feelings of disappointment and emotional pain:

(What about your friends?) You know what, they pretty much disappeared, especially his friends. I think people are afraid. So we’re not too social now. (Elaine)

(Any other changes in relationships, say with family, you mentioned friends?) Oh ya, there was one member of the family that was involved in the shenanigans so that relationship is strained to the point of non-existence. (What were your biggest struggles in that process of Mary getting sick?) Well we had one big struggle, a small
group of friends, now former friends, who took it upon themselves to conclude that I wasn’t pulling my weight. It was a group of three friends of Mary’s well couples that we had been friends with for years and years and years. You know we had a good friendship, and silly me, I thought they were helping out of the goodness of their hearts, but all the while they were analyzing, assessing…to use a direct quote, “Doing their own research” and reaching their own conclusions; never really talking to me much about anything. So, because I wasn’t here all of the time, since I didn’t quit my job, the one person said, “You didn’t go on sabbatical.” Well you don’t go on sabbatical if you are in business, maybe if you teach, you go on a long term leave and even then that is iffy. So I was functioning under the direction of our rehab hospital team. This was happening after Mary was released as an inpatient and was then an outpatient. So she was here, still confused, she was just a couple of months post trauma. So confused, upset, she would get angry sometimes. So this individual used that access to get to the physiotherapist at the rehab hospital and phoned with this group’s long list of complaints about Mary about me, about how things were going. They called it the intervention and they said that they were just helping out of the goodness of their hearts, the therapists with their therapies. What happened was that Mary’s progress went sideways for about two months, until we pieced everything together. (Mike)

There has been one particular couple who just didn’t get it, which was very disappointing because they were the last people we thought who would do what they did. Well when Carl got sick, they lived close to us. Right away they offered to help
with the kids, pick them up and feed them and all of that. I didn’t ask them, that’s the type of person I am, I will not ask. I will ask people that I feel will not hold it against me, unconditional…and I have friends like that…and vice versa and I am not going to do something for you and expect a bouquet of flowers. Anyway, they offered to help and of course there was really no end in sight. One night they came to the hospital and Carl had probably been in about a month at this point, he was still not well at all. I was exhausted and emotionally drained. They wanted to talk to me, and wanted me to go down to the coffee shop, so I went. They proceeded to lecture me because they thought I was spending too much time at the hospital and that my children needed me, particularly Candy. And I knew they were helping, having the kids for dinner when they could…I was just so upset and Carl had been having a horrible day… Then the husband called me up, his wife didn’t and she’s my friend and I thought that was really weird. He said we’ve been helping making the dinners for your kids…their kids were grown up and moved out…he said you know… I know we’ve been helping but we really can’t do it anymore, having the kids over for dinner is a little bit overwhelming for Carrie. It’s overwhelming?? I thought, its overwhelming making dinner once or twice a week, while my family is in crisis. I was so upset, but I said no problem, I said, don’t worry about it, we’ve got things under control now. I remember I was so upset when I got off of the phone that I was crying, I was angry, I was mad and I was hurt. I thought how can you do that to someone, you know, he (Carl) was in ICU and fighting for his life every day. (Claire)

An important discovery that emerged through discussions of supports and changes in relationships was that the participants became responsible for managing all of the
interpersonal relationships for the couple. This was a new role requiring a transition as the brain injured spouses managed their own relationships prior to the injury and shared in the management of shared relationships. Taking on the management of more interpersonal relationships creates more possibility for interpersonal conflict and thus increased stress for the participants.

**Small story two: Feelings in the Immersed Caregiver phase.** As would be expected the participants reported experiencing a large continuum of emotions in this phase of caregiving. They discussed the various causes of their feelings and how they attempted to manage and cope with those feelings. Many of the feelings were consistent with the prior phase however the underlying sources to these feelings were different in some respects. As they moved out of the crisis phase of the medical emergencies the spouses also had more time to reflect on their feelings and hence there was an increase in interpersonal problems. Perhaps the time at home adjusting to caregiving roles lead to them spending more time ruminating over feelings and hence more frequent discussion of feelings was noted in this phase.

**The spouses experienced continued feelings of stress.** The participants discussed how the changes in their spouses resulted in the experience of stress because they had to manage many more tasks and roles within their home and social lives. Taking on the role of being in charge of the entire household emerged as a significant source of stress and anxiety feelings.

*(What have been your biggest stressors?)* I think being the emotional pillar of the house. Everyone’s needy sometimes…my daughter needs me in bed with her, my son needs me to put him to bed and to watch him fall asleep. Isaac needs me and my older
son…I always feel I don’t have time to talk to him. Spreading myself between all of them…sometimes they all want to talk to me at the same time and it’s hard to be there for everyone. (Inga)

I really started to suffer from post traumatic stress. I just found that after eight to ten months that emotionally I was just a train wreck. (What has been your biggest transition since the accident?) That’s a hard one…doing everything by myself. It’s been especially hard the last few years because both of the girls are gone. (Janet)

(Tell me about what’s been the most stressful for you.) I guess just dealing with her sometimes. It’s like with a child, except you can teach them, you are not teaching this, she’s not going to learn, and that can be frustrating at times because you tell her one thing over and over. So most of the time you let it ride, unless it’s going to burn the house down, you learn to let it go. (Kyle)

The spouses often felt misunderstood by others. The participants discovered that it was often hard for others to understand their situation and new roles with their brain injured spouse. Ultimately, they described a lack of empathy in others that negatively correlated to offerings of support from family and friends. As the spouses felt more misunderstood, the more changes they observed in their interpersonal relationships:

(Have you met anybody, who hasn’t had this happen in their life, who get’s it?) No. Most people think when they talk to Al, things appear other than they are. Well you get one of two reactions. One because his speech is slow, they think he is stupid so people raise their voice to speak, that I find annoying. The other, well have a friend
who just doesn’t get it, her husband takes her car to the gas station to get gas for her. I
work for her and she added more time, then I saw her husband and he asked me how I
was, I told him I was exhausted. The next day she told me her husband was mad at
her because she hadn’t noticed how exhausted I was. She doesn’t get what I’m doing.
(Anne)

But other people I don’t know. I guess they realize that something is different. I doubt
they understand to what extent things are different. It’s hard to imagine unless you’ve
been there, like having a disabled child. Very good friends of mine, they had a
disabled brother. I saw him last night it was fine because you get to go home at the
end of the day. But until you have one yourself, you don’t realize what a change it
makes to your life. (Kyle)

Things have changed in the way that they don’t truly understand what the situation is
on a daily basis. They see her on occasions etc. and she functions reasonably well,
and they will ask her if she remembers a certain event and she will say yes or partially
and they accept that even though she may remember absolutely nothing…because
when I question her that’s usually the case. I think her sister especially, who is
extremely helpful, doesn’t want to hear negative comments. I think I tend to be more
realistic, I say this is the way it is, she doesn’t remember anything, and we have to do
everything for her. You know her sister will give me 10 reasons why she (Denise) can
do this or that, which is true, she can but it’s just not realistic for survival without
help. (Doug)
The spouses experienced feelings of guilt when immersed in the caregiving role. The spouses discussed feelings of guilt that they had, and, there were various sources for this guilt. Because the spouses were required to immediately transition into new roles in response to the changes in their brain injured spouse feelings of guilt arose with respect to new roles. However, in some cases the guilt stemmed from having negative thoughts about their new life situation.

(Tell me more about what the guilt was about.) Well sometimes it’s about having that little Gazoo type character saying to you, “It would be easier if he wasn’t here.” Guilty for feeling that way. (Heather)

(So how do you feel about having to walk him through those steps every day?) Some days I don’t mind, and some days I lose patience and I’m like, “Christ come on I’ve got work to do,” and then I get off the phone and I start doing my work, and then I feel bad for yelling at him, so I phone him back to apologize and he doesn’t remember that I yelled at him anyway. It’s just very frustrating, but there’s nothing you can do about it. What do you do, you grin and bear it. I feel really bad for him, it’s not his fault. I think if he really understood, I don’t think he’d want to be like this, he wouldn’t want to live like this. He has no quality of life. So I try to balance it out. Sometimes I have good days and some days I don’t. (Gertrude)

Opportunities to go out without the brain injured spouse lead to feelings of guilt for the spouses. The guilt feelings were complex and contributed to feelings of loss and grief:
Both of my kids though, my older one is engaged and will be moving out, so I don’t know what’s in store. Right now I know someone is with him when I go out but the girls won’t be there much longer. I went out before (the injury) but he could go out. Now he can’t so I feel bad if I go out too much. So I go out, but certainly not as much as I would like to. (Anne)

My big thing is that I feel guilty because I think, “Oh poor him, he’s going to remember how he used to be, he used to drive a fancy car, he used to do this, he used to have a great job, he used to fly everywhere”…and now…it’s not like he doesn’t have anything but he has none of that. How’s he going to feel? (What would the guilt be about?) Leaving him. He needed somebody and I was it, I was it 24-7. So I mean how could you leave somebody in that state and say, “Fend for yourself I’m out of here?” I mean, I loved him, how could I…I couldn’t do that. (Lisa)

The particular role of being responsible for their partner’s rehabilitation caused the spouses to experience guilt and internal conflict because they often felt like they were letting their spouse down when they could not fulfill the task requirements for this role adequately.

Well if we took the time and stayed home and did the physio then he could probably walk. So we’ve kind of gone backwards physically from where he was when he left the long-term care because we don’t do it (the exercise). So there’s a lot of guilt from that, that I feel. I feel like it’s my fault because he doesn’t have the motivation to say that he wants to exercise or walk. So I feel like that is on me, you know like I’m responsible. (So tell me more about the guilt.) You know I feel guilty just about that, and I’ll always say to him, “Ok tomorrow you are getting on the bike and we are
going to walk,” and then we don’t, and then I say we are going to start staying home because every day we are out. You know we can’t do it if we are out every day because when we get home I am tired and I don’t want to do it. That’s the only thing I feel guilty about. Well I like to sleep in and he likes to get up. So as soon as I’m awake I feel like I have to get up to get him up, so I think just five more minutes and you know he doesn’t care, he says, ”Just stay there don’t get up.” It’s a little bit stressful but I know it doesn’t really matter, sensibly I know I have nothing to feel guilty about. But when I get him on that bike, god does it feel good—so why don’t I then? It’s hard to feel like you are responsible for somebody like that. (Elaine)

He’s put on a lot of weight in the last few months. That is a worry because I feel that God has given him his life back but there are some things we have to do like diet and exercise, which …I feel if it’s not happening it’s my responsibility. (So you feel a sense of responsibility for his total health?) Yes. Because with the disabilities there is really nothing we can do, but for this (diet) we can do it...Well he has started going to the gym in his mom’s condo, it’s just a better environment than working on the treadmill at home. I have to get him doing this; it’s a lot of work. Even, the level of exercise that is required, he would be happy to have it at a lower level. But in order to have it impact your sugars and whatever, you have to have a certain pace and heart rate and everything. He doesn’t keep track of the numbers so I have to do that. So I’m not going to push him on things…for one thing it severely damaged our relationship when I pushed him hard because it has to reach a point where they want to do it. So if
he’s recovered without any therapy at all, who knows what will happen just by letting things be. (Inga)

They often became frustrated. Many of the spouses reported feeling frustrated and angry due to many different scenarios that they encounter in their daily lives. Many reported feeling frustrated by the lack of knowledge about the next steps in recovery or constant changes evolving in their homes. Frustration was also discussed in the context of being immersed in the caregiver role for their spouses.

Back then, the frustration and the anger I felt about not having a defined sense of direction or where I was going or what was the next step… that I think freaked me out the most, that there was nothing in place to tell the spouse what the next step was. What do you do from here? So now you are here and you are in rehab, so what happens now? You are out of rehab, “Hold on a second, I can’t bring him home, I have to go to work, and now what happens?” Well you’re going to do it because you signed up for it, you signed the paper, and it was your name on the forms that said that he could have the surgery. Then it was like… “What do you mean he’s not answering the door? When I left he was just finishing his shower, now its noon and he’s still in the shower, can you please get him out?” This is just a vast amount of things that have happened and it’s really hard to know what’s going to happen next. (Nina)

Well it kind of frustrates me but I am used to it now. We just say two words and that, or I call her during the day; it has been easier for me to adjust than the kids. It is not as frustrating as before when she used to call every two minutes and leave messages,
but now it’s more of a routine, I will call her or she will call me. I finally got her to start using the internet again so she will email me asking how it’s going…its small things at a time, but we are definitely seeing some improvements. I was told there could be improvements throughout her life; it could be gradual changes throughout. (Frank)

But there’s many days where I get in my car and feel like I just don’t want to come home, and some days when I am home and he asks me the same question fifteen times in five minutes, I feel like throwing him through a wall. But then, you just gotta think, it’s not his fault. I do have my moments but not very often. (Gertrude)

*Feelings of exhaustion.* The spouses described the numerous new roles that they had to take on within their household. Eventually, taking on those new roles in addition to caring for and/or monitoring their brain injured partner lead to exhaustion. Many of the spouses indicated that their exhaustion was directly linked to being immersed in the caregiver role and taking on numerous roles. Taking on all of those roles subsequently lead to feelings of burden.

Well, sometimes if you don’t sleep well then your exhausted just because. I am generally a good sleeper, but we have a couple of cats that wake me up, so I’ll get up to feed them and if I don’t go back to sleep right away, I start thinking of all the problems, all the finances, all the things that need taking care of, all the problems that are going on. I’ve tried those games of putting those problems in a box and putting them under the bed but that doesn’t work for me. When you haven’t had enough sleep
because you are thinking too much and you get exhausted from that, um, I’m tired because I am running around behind someone else and I am emotionally tired. (Anne)

I’m it! You know, chef, cook and bottle washer, that’s me. It’s everything; I’m responsible for managing the household, the finances, helping the kids. I get all kinds of emotions about it, I get angry and I’m tired, really tired. It’s not just managing things at a high level but at a tactical level, like getting the garage cleaned up. Our property needs a lot of work…I took him to see friends; I took him to appointments…On top of all of the appointments I would take him to a familiar place, just to get him re-acquainted to the normal parameters of our life…I think what happened to me is that I got exhausted. I said to a friend, I have so much stuff to get caught up on at home. I said; imagine having left your own life behind for two years…so I finally realized I can’t do this anymore. (Claire)

At times, I’m tired, exhausted by the end of the day. You know you have a plan, a schedule of things you want to get done by the end of the week, because you don’t want to spend the weekend doing it. I do feel exhausted. (Frank)

**Feelings of loss evolve and change.** In the initial years, the brain injured individuals reach their potential with regard to cognitive recovery possibly making small gains in the years to come. In this Immersed phase the spouses watch their spouses’ progress in their recovery while dealing with the changes and losses in their lives. New losses are experienced as time passes and old roles are not resumed by the brain injured spouse. Thus, the experience of feelings of loss from the Embryonic phase to the Immersed phase appears to
intensify and further contribute to the spouses’ overall experience of grief. Furthermore, the changes in relationships described in the section on stressors also contribute to feelings of loss. The well spouses were hurt and experienced grief about the loss of connections with certain friends and family members.

(So how have things changed for you and your family now?) Pretty drastically, pretty dramatically…I mean with the whole dynamics of the family. Before Carl and I were pretty much partnered, for everything that we dealt with in our home. From tactical to relationships, dealing with the kids, to managing the household, that’s all shifted now, shifted to me. (Claire)

I miss having that partner to problem solve, to do parent strategies with. To sit down, you know when the economy took a nose dive, it was like oh my god, we lost so much. All of a sudden…I phoned up our stock guy and told him that we had lost half, it was like… I went into panic mode. I couldn’t talk to Oscar about that, partly because I didn’t want him to worry. But it was all on my shoulders, I’m now responsible for everything, really, really I am. So if I make a boo boo from an investment point of view…I have more of an appreciation for what men do in relationships stereotypically, for feeling like the weight is on my shoulders. I mean I can’t retire, not that I would retire right now. (Olive)

Small story three: Supports in the Immersed Caregiver phase. The overall focus of the participants’ reports regarding supports during this phase changed from the first phase. The data revealed that the well spouses tended to reduce their engagement with social supports such as family and friends and spent a significant amount of time engaged with
professional supports such as rehabilitation and treatment teams. They appeared to be more selective about social supports and this stemmed from stressors related to changes in these social relationships. For the participants, returning to work or not returning served as source of emotional support.

**Working during the Immersed Caregiver phase is a source of emotional and social support.** In the Immersed Caregiver Phase returning to work was an issue that became a necessity to address because many spouses had run out of sick leave time. For some, the financial pressures were starting to increase, and for others there was a need to return to a productive work role. Many of the participants did not quit their job in order to adjust to their new life situations. Some stayed working for financial reasons and others stayed for personal reasons. Whether the spouses worked or not, they maintained their immersed caregiver status. The impact of having a brain injured spouse on one’s ability to fulfill work roles was discussed:

I would be the one to drive her down to rehabilitation, help her get settled and then go off to work. At the time I was working about an hour away from the hospital but it was usually a reasonable drive. When she was in the hospital I was back and forth every day as well. I would go into work in the morning, I am in consulting so there was a… it was a perfect storm… we were working on the largest project our company had ever taken on and I was in charge of the team, I could have said “No I can’t,” I really could have said that, but we were given advice that you really shouldn’t drop your pencil to become a full time nurse almost because the intent of the rehab hospital was to help the patient rediscover what they had pre trauma. So to have a full time husband doting over her all day just wasn’t pre trauma. So that’s the advice we were
taking…So I couldn’t just not see her, so I drove to the hospital every day, one of Mary’s sisters was there for the morning, and I would go for the afternoon and head home. *(Did it impact your work, in terms of getting things done; did you have to scale down?)* Yes definitely I had to scale down but my work was very understanding. I delegated a number of projects so I could focus on this one, and that suffered in my ability to really deliver on that job a little bit, well probably more than a little bit. We got the job done but it was tough. *(Mike)*

I juggled my work schedule to support her needs. I changed my schedule to get her to her appointments. Basically we would go first thing in the morning so I could get to work. So 8 o’clock in the morning, we still go at that time…it is difficult on her but it helps me. I work in banking. They were pretty good, they allowed me to adjust my schedule and take time off here and there initially. The first three weeks I was at the hospital, and after she started her therapy, I would go in after work because we knew we had the support there. When she came home, I took her to therapy first thing in the morning and then dropped her off at my mother’s house because she couldn’t be left alone. *(Frank)*

Me going back to work which was huge. In the winter I only work for seven weeks …. So I thought it was the perfect time to go back, also that’s when Henry had moved to the Rehab hospital, so I thought it would work. At first I thought I may not see him during the week, but I ended up going down on Mondays. I would take the go train down and stay until he would go to sleep and then I would come home. Going back to
work was really good for me…Just because I have my friends at work, they were very supportive. My office mate, her father had been ill the year before and I had been there for her, you know making sure, she was ok, asking her to go for a tea, or making sure she ate and had lunch. She said you were there for me and will be there for you, so she just did the same thing. So work was really good. (Heather)

**Not returning to work was also a source of emotional support and stability.** Some of the participants preferred to give up working in order to care for their spouse. They expressed concerns about others being able to adequately provide care or the financial implications of hiring care. Transitioning out of the working world maintained these caregivers in the immersed role as they chose to focus on maintaining their family unit, and this sometimes lead to being temporarily disconnected from the rest of society and/or their immediate community, however, they seemed to prefer to remain connected to their nuclear family unit as opposed to reaching out to the outside world or external social supports.

*(What has changed since the time of Beverly’s injury, tell me your story?)* Well I haven’t been back to work since then …they have been nice to let me stay off all of this time. I did get my ducks in a row I have gotten doctors notes etc., everything, it was good to get that to make sure I could stay off work. I’m fortunate; you know my work hasn’t bugged me. Once I was off of work for a year, they could see I wasn’t coming back so they had me sign a contract stating that I am retired. They back dated some pay etc. so it worked out well. You do have to get the medical association behind you which I did. My doctor was supportive to fill out the documentation. Going back to work just wouldn’t have worked, given the hours…I trust my kids and all but it would have been long hours away and a lot of responsibility for them. So I
think I’m fortunate because I don’t have to work, it would have made it a lot more difficult. Retiring wasn’t my plan but it has been 30 years so I’m okay with that. The pension and the benefits have left me sitting really well. I don’t have to worry about the future, so I am fortunate. (Bill)

I took a leave because, when Carl first got sick, I kept saying I’ll be back in a week, I’ll be back in a week but it just wasn’t happening. It wasn’t just the time commitment for Carl; I was just so stressed out. I have worked in environments where it is so deadline oriented and very stressful and talk about multitasking… because of the type of work I did and the visibility that it had. I think I just got burnt out and the stress of it all finally started to hit me. So I started a leave, a leave of absence and at that time you know I thought maybe three months, then it was 6 months, then it was a year. Then of course, here we are (three years later) and I am just, just starting to think about doing something for myself again…but I’m scared. I say to myself, how will I fit it all in, and I have grown children…I’m on long term disability leave but in fairness to the organization and even me, I know that in the next few months I need to make some decisions about what I want to do. You know for my career, I was just getting to a point where I was thinking of moving to a consulting firm, which is what I always wanted to do. I had worked for a year on my degree and had done a certificate which took a year and that all stopped. Now when I think of going back to complete that degree, I don’t really know how that would be possible. I had been talking to a few consulting companies about moving and I still think about that but now I’ve been out of the field for so long I don’t know. (Claire)
As far as I am concerned it is more important to look after him and take care of the family than to work, because my daughter is so little. I might consider going back to work once she goes to full day school. As of now, for the next year or so I will be home…well and I haven’t worked in seven years. (Inga)

**Narrowing social supports.** The spouses appeared to actively reduce their engagement with the number of social supports they needed compared to the Embryonic phase. This may have occurred for many reasons such as: not wanting to continually ask for help from others, deteriorating relationships, reduced time, enhanced skill mastery, or having a desire to manage independently. Irritations in relationships also spurred these decisions to reduce contact with certain friends or family:

Well I have a friend who just doesn’t get it; her husband takes her car to the gas station to get gas for her. I work for her and she added more time, then I saw her husband and he asked me how I was, I told him I was exhausted. The next day she told me her husband was mad at her because she hadn’t noticed how exhausted I was. She doesn’t get what I’m doing. I don’t need that… (Anne)

His own brother was very helpful at the start but in all honesty I have sort of drawn a line in the sand with him because if Henry wants to see him that’s fine. He hasn’t been very helpful since January on…He lives down the street from us. So I guess I’m a little bit, well you push me to a certain point and I am done with you. Henry will forgive and forgive and forgive. I’m at the “I’m done with you” point from here. (Heather)
Maybe five months after the fact, the husband of the ring leader, who was taking orders from the ring leader, wanted to resolve things and rekindle the friendship. We had a lunch and it was almost like the accusations were still there, there was no interest in listening…and I’m listening and I say, “Why am I here, I’ve got far too much going on to listen to this.” (Mike)

Some spouses felt that family members coddled the brain injured individuals with stunted their progress. On asking in-laws to leave:

His dad…I finally had to tell his dad to stop shaving him and feeding him. Yah that was one of the hardest parts was trying to deal with people. (Elaine)

You know he needs to be on his own, come September he will be on his own because I’ll be back at work full-time. I said, “He needs to start doing these things.” His mom was really hesitant but they did go, and again, huge improvement. (Heather)

The spouses discussed their reasons for seeking out less social support. Some wanted to be more self-sufficient and less dependent on supports, while some lacked time and others wanted time to themselves:

My friends are there, but I wasn’t really…I have friends that are separate from our family network, but my time is so, such a rare commodity, …me going to have lunch with an old friend, or me going to have lunch with Odessa, you know like…I chat on
the phone with them briefly…they’re there. I know they are not the type of friends who would say, well I haven’t heard from you in three years, like what’s your problem…but they are definitely there, they are there if I need them and I am there if they need me. (Olive)

I think because, we’re quite different, give me a book, I’m perfectly happy to stay home and put my feet up and read a book. Edward wants to go, he’s a goer now. So I’ll take him out and drive him around the block. So that’s the problem that we will have, finding the balance so that he can get enough stimulation, and me just being left alone. (Elaine)

(Have you had the support that you needed from family and friends?) I haven’t asked for any really. Her sister I expect a lot more support and help, however, she lives on the same street as her mother who just got diagnosed with Alzheimer’s disease, and she’s a lot of trouble. So she (the mother) is taking up a lot of her energy. So I kind of expected that I would be left to take care of Beverly, I realized the help wasn’t coming and I just adjusted, you know it is me. My mom and dad live out a ways but are supportive. Everyone is generally supportive but the daily stuff, the tasks it is all me and its fine. I’m quite used to it. (Bill)

On not wanting to burden friends and family:
One of my neighbours offered…he said if I was stuck once I go back to work, that he could bring him one day a week. I said, “That’s great”, but I’m very independent and I don’t like to ask people for help, so I’d rather see if I can switch the day first. If there’s a day once we switch it where he could help me, then I will ask him, but I like to do it myself. Other people have said to me why don’t you call. For example, Harriet and I cut the grass because we have a huge back yard, but between us, we are cutting the back yard. I don’t want to be the person that you see the phone and you think, “Oh it’s her calling, what does she want now?” (Heather)

Friends are great in the beginning but life gets back to normal for them. So some of them disappear because they can’t be bothered and some of them stick around but you don’t want to appear whiny. So even though you still have those friends, your relationship with them changes too. (Anne)

**Small story four: Pursuing independence for the brain injured spouse emerges as a marker for a transition to a new phase.** Eventually, the well spouses realized that it would be beneficial to promote independent thought and behaviour in their partner in order to foster their recovery and to try to maintain old roles and life routines. That data suggested that fostering independence in the brain injured spouse helped to reduce the role load for the well spouse and perhaps eased or buffered some of the perceived losses that had been endured. Thus, promoting independence in the brain injured spouses became a process of transitioning into yet another role for the well spouses.
I said to him, “You need to try, you need to try to do things, I am not your mom, I am not going to spoon feed you like your mom does. If that’s what you want, then you pack your bags and you go and live with them, and you live a simple life with them. But if you want to get better and live as close a life to what things were, then you need to try.” Then he said, “Ok” and that was a real turning point with things. I do have him do things. We bought a BBQ and he assembled the BBQ, and a cupboard he put together. He put a new faucet in Harriet’s bathroom, now granted it took hours, but he did it. Our faucet in our bathroom was plugged and he took it apart and unplugged it. I thought, “Ok he’s not going to be able to put it back together again,” but he did. I try and push him as much as I can to do normal stuff. (Heather)

It’s very…what’s hard, is to figure out is how much do I let him manage his own life; versus how much do I take responsibility for him because I am in the difficult position of being both the caregiver and life coach. So how much do I push him and how much do I take over? He’s doing palm pilot training right now and I’m really hoping that that helps. I think after some time, you stop seeing it (the medication signs on the wall); you know mentally, you tune it out. If you are not really interested in it…for example, he plays for the church, he knows Thursdays, that’s what he does, so he’s tuned into Thursdays and asks, “Ok, when is Ike going to pick me up?” Sometimes I’ve taken the route of letting, allowing Isaac to …of not making too many accommodations for him in order to allow him to adapt to the situation, rather than protecting him too much. One can get too protective; I know his mom is too protective. I sent him once with Wheel Trans, and she was like, “What if they take
him to the wrong place and what if they do this?” and I said, “No, he’s a man and he’s got to get used to it.” He’s after all my husband and he’s the protector of my home and I don’t want to take that role away from him. I have to push him, I want him to go on the TTC by himself, he hasn’t done that yet, but I think he has to do it for his own sake because I know that would make him feel better, and his therapist says it’s ok. But it’s still hard for him to push himself to do that and his mom would be like, “No!” there would be a crazy fight over it. Unless he does it, he is not going to move on. (Inga)

Well this has been five years, and we have celebrated the five year mark and thanked everybody for helping us, but where do we go from here? What’s out there? Well there’s not a lot out there but there’s still a lot that needs to be done for him. So what do I need to do, I need to get him to be more dependent on himself as opposed to dependent on me, because he will tell people, “She’s my memory, if it wasn’t for her..” I don’t want it to be just because of me, I want him to be able to take care of himself. (Nina)

The findings suggest that essentially, the spouses may come to a point where they recognize the importance of creating opportunities for independence for their brain injured spouses. This process could be likened to the analogy of raising a child where it is bitter sweet to foster independence as one loses the opportunity to care for their child; however, independence is recognized as an essential part of autonomous living for that individual and for some, the freedom of having less caregiving roles is welcomed. Once the well spouse was able to recognize the importance of establishing independence for their partner (not all
participants in the study had reached this phase due to the early stage of caregiving or continued difficulties in caregiving), they began to modify their role as caregiver, and hence transitioning into the Modified Caregiver Role. This transition involved shifting from a reactive crisis oriented caregiving mode to a more proactive and planning focused caregiving mode.
CHAPTER SEVEN

RESULTS

Overview: Ebb and Flow of the Modified Caregiver Phase

Once the spouses had time to reflect on and understand the series of changes they had endured over the months or years post injury, many began to engage in a process of reconciling their losses. The marker for progressing into the Modified Caregiver Phase involved making attempts to restore balance in their relationships with their partners, and beginning to focus significantly more on establishing independence for their brain injured spouse. The roles taken on by the spousal caregivers throughout the caregiving trajectory appeared to be cumulative right into the Modified Caregiver Phase. Thus, in this final phase, the well spouses began to renegotiate and reduce their caregiving roles. There appeared to be less new external stressors in this phase and the spouses were able to focus their attention to more positive aspects of life. They had a tendency to reach out to social supports in different ways than the other phases and they also developed ways to find support within their own homes.

Not all participants in the study had reached this phase in the caregiver trajectory as some were just a few months past the onset of the injury. Some participants appeared to move back and forth between the Immersed and Modified caregiver phases, thus, it was not clear if all the caregivers reached a fully modified phase or if some spouses constantly transitioned between the immersed phase and modified phase on a continued basis, depending on their ability to negotiate roles such as fostering independence and arriving at acceptance (see Figure 3).
During the Modified Caregiver Phase, the well spouses start to think about how to bring more balance (decision making, power dynamics) into their relationship with their brain injured spouse. Concepts that were valued and pursued included joint decision making and parenting; improved sexual relations; improving daily functioning; engaging in independent and meaningful activity (brain injured spouse); and focusing on the positive aspects of life while doing enjoyable things together.

**Small Stories: Emerging and Continued Themes in the Modified Caregiver Phase**

Role transitions in this phase sometimes focused on transitioning back to old roles and/or promoting the engagement in independent roles for the brain injured spouse. The roles within the context of sexual intimacy were addressed by many participants, because a significant amount of ambiguity related to power dynamics arose from the new dynamic of being a caregiver and a spouse. It is likely that this dynamic was discussed more by individuals who had reached this phase as the burden of caregiving appeared to be less immersed and more focused on reducing roles for the well spouse, thus leaving more time to address less life threatening issues such as sexual intimacy. Of note, it appeared that
participants thought about this issue during all phases of the caregiving continuum, but were most likely to begin to address it at the Modified Phase.

**Small story one: Stressors in the Modified Caregiver phase.** During the Modified Caregiver Phase, the spouses appeared to be more focused on finding independent and meaningful activities as they became more focused on achieving balance in their relationship and out of their continued pursuit to improve the quality of life for their brain injured spouses. The level of impairment in cognitive functioning in the brain injured spouse moderated their ability to increase their independence. Thus, some well spouses moving into the Modified Caregiver Phase struggled in their pursuits for independence for their partners causing them to fall back to the Immersed Caregiver role while attempting to address this issue. Thus, for some participants the process of developing independence for their spouse was a stressor. Many well spouses ultimately enlisted the help of other supports such as family, in attempt to reduce their caregiving roles. Others who had to rely on community supports were less successful as they had difficulty finding appropriate services for more severely amnestic individuals in the community.

**Finding productive, independent and meaningful activities for the brain injured spouses is a stressor.** In this phase, the well spouses begin to evolve and discover that meaningful activity will enhance the quality of life for their brain injured spouses. For some of the spouses, they may have considered this concept earlier in the caregiving trajectory however the number of other more pressing stressors interfered with their ability to address this issue. As things slow down in the Modified phase, the well spouse found the time to look for meaningful activities. However, due to the lack of formal or appropriate opportunities in the community in this area, searching for productive and meaningful activities became a
stressor. The brain injured person’s lack of ability to contribute to this process or reluctance to engage in activities also complicated the aspects of this stressor.

I guess the one worry is will Mary ever get back to the point where she could do something for her? She does a lot of things, but she does get frustrated, she says she gets bored, but at times she’s still reticent to go out. She’s on long term disability but it’s only a little bit and it’s not like we need that money. So that’s a worry, you know will she ever get to the point where she is productive and feeling good about herself in that way again. (Mike)

If I could find him a niche where he was doing something enjoyable or productive, I think it would make me feel better. If he’s happy then I ‘m happy and also I’m not guilty because he has something to do. My kids I think would be happier too because they could see him in a role…at the same time though, he seems happy enough. (Anne)

The other piece about our relationship that’s changed is that Oscar’s retired now; he’s retired earlier than he planned on, and I’m not retiring with him. If Owen was in university and I was retired, that would have been a simpler situation for me right? Because we would go away for a week and do a retreat or do art classes together or I would go travelling with him, we’d do things together. But I’m still…there’s a difference between our ages anyway, but I’m pretty much still in the workforce, and I’m planning to stay there. So that’s changed our relationship because he’s at home, without being able to initiate his own retirement. So I’m also planning for his
retirement, I’m putting things in place for the next stage; I am finding volunteer work for him, and stuff. I’m now ironically…I was always wanting to plan his life for him and now I am getting to do that…but I’m saying that jokingly because I really don’t want to have to do this. I’m having to guess what Oscar wants to do because he’s not coming up with his own ideas. (Olive)

Not being able to find appropriate services over time in the community to promote meaningful activity was stressor. Initially many spouses found that there were few opportunities for independence and finding meaningful activities for their spouses. Some attempted to utilize resources in the community that they eventually found to be inappropriate, creating the stressor leaving them feeling frustrated:

With Al being younger, the programs that are out there are for seniors or for people with brain injuries with a different level of functioning. So for enjoyment for him is not sitting with 75 year olds or people that can’t function. (Anne)

So I would take him to a day program and then I would see the people going in and out of there and I would start crying because I would think this isn’t Luke, like he could still function. So I took him to one and he just went and slept the whole time he was there, and they would tell me that he wouldn’t participate. So I didn’t know what to do with him…All of the day programs that I’ve tried, he was too young or too high functioning. He went to several in various cities and hospitals and he just would not
go back, I could see some other people coming out of there and he was just not that bad. (Lisa)

So he had a health recovery group and everybody in the group had Parkinson’s and they were quite elderly. Everybody assumed Oscar had Parkinson’s and that was really confusing for him, so it was very awkward. (Olive)

*Searching for opportunities to promote their brain injured spouse’s independent role in decision making can be a stressor.* Many spouses tried to keep their spouse immersed in decision making for the family, hoping to foster independence and self-esteem. Some spouses tried to actively engaged their spouses in decision making earlier in the caregiving trajectory, however, they appeared to be more focused on this issue in the Modified phase, and they had master more skills in this domain by this point. They also tried to maintain the brain injured spouse’s old roles in order to return to as close as possible to living the way they used to live. Not achieving this goal for their spouses appeared to be a stressor.

I guess I have more authority because I have to make all of the decisions. You know, we involve her as much as we can in everything but when it comes down to it, it’s me who decides. (Bill)

I think I’m more devious now. I try to let Luke make a decision, but I try to …well I want the decision made, but I give it to him…you know what I mean…I want him to come up with the same result that I have. I want him to do it. To help him feel like he has more control. And he does have control because he makes all these arrangements
for him and Lance; I mean he is on top of things. I have to give him credit; he’s come a long way. (Lisa)

We try to involve her so that she doesn’t feel neglected. Whenever we make a decision we involve her too. Right now we are doing some work around the house, changing windows and that, so we involve her as well and at least she feels important as well. So that’s important to us. (Frank)

**Continued management and monitoring of the brain injured spouse’s health is a stressor.** The spouses who appeared to be in the Modified Caregiver Phase, reported that they continued to worry about their partner’s future health and the potential for more health problems. As they progress in the Modified Caregiver Role phase, the well spouses focus more on the limits of their partners’ recovery and they begin to develop worries about their spouses’ future health concerns:

You worry if he is going to get sick again. Every 6 months we do cat scans and MRI’s. The day that they tell you that this one didn’t go all right, I think am I going to be able to go through all of that again. Do I have it? If he were to get bad enough that he would have to go into a wheelchair I worry about those things. (Anne)

I see there is potential for other brain related issues, her aunt has Parkinson’s and this is a worry for me because Denise already has had brain some damage…you know it could come, I think of that potential. I also worry about whatever damage is there that you don’t know about. (Doug)
The well spouse's health can sometimes be a stressor. The well spouses also seem to spend more time focusing on worries about their own health during this phase, and they appear to transition in and out of the role of forward thinking and planning. As discussed in the Common Issues Impacting Spouses Throughout the Caregiving Process chapter (Chapter 4), many of the participants did develop health problems during the many years they had been caregiving for their spouses. Thus, it is not surprising that their tendency to reflect on their own health in this phase may be a stressor as they may have neglected their own health problems for many years. This self-reflection and subsequent development of a stressor is a change from earlier phases in the trajectory where the spouses indicated that they were completely immersed in the moment and on daily needs and issues. Worrying about the potential that they might become ill or die and the impact that would have on their children and brain injured spouse moved to the forefront of their thinking. On thinking about the future:

If anything happened to me, my children would have to do it and they wouldn’t know what to do. I know who to call right now, so I will have to leave a list for them to start the process. So hopefully I will be here they won’t have to. (Janet)

At this point I am more worried about how the family would be in trouble if something happened to me, that’s my main worry…especially with my mother and Denise, what will happen to them? (Doug)

Yah, I guess my worries are about if something happens to me, what next, what happens to her. That would be challenging…there’s my mother but my mother is 75.
There are always those things in your mind; you know what would happen to the kids if something happened to me. So there is always that worry. (Frank)

**Reduced sexual intimacy can become a stressor.** As discussed in the Common Issues Impacting Spouses Throughout the Caregiving Process chapter (Chapter 4), changes in sexual intimacy are present throughout the continuum of caregiving. For some of the well spouses, this issue becomes a stressor to address as there is more time to focus on this issue and the longer period of time passed contributed to their worries about the complexity and potential resolution of this issue. The loss of sexual intimacy in a couple’s relationship alters the dynamic of the relationship. This creates a new role for the well spouse because they are left to always initiate sexual intimacy or to discuss the lack of sexual intimacy. The well spouses become uncertain about how to address the problem with their spouse because it is an upsetting topic, and can subsequently cause distress for their spouse. Thus, the well spouse is forced to carry the burden of this loss while still be “in charge” of deciding how or when to be intimate.

He doesn’t even talk about it anymore. See that’s one thing I can’t even talk to him about that anymore (sexual intimacy), we used to talk about it but now it’s become that thing we don’t discuss. I don’t know if he even thinks about it or if it’s just me thinking does he think about it? But I don’t even really think about it anymore… I think it’s his innocence…that I would think he would find me a dirty old lady. It is something to do with the roles that have changed. (female participant)

*(Is it [sex] something you are able to talk about with him?)* Yes and then it makes him feel bad. You forget and then you go on to tomorrow and how many times do
you want to bang your head against the wall and get yourself emotionally upset? We work on it, working on it is better than ignoring it and letting it become a festering boil. (female participant)

Our sex life has changed… (Are you able to talk to him about that?) No, I joke with him about… “Oh we should start having sex sometime” I think… it’s just that energetically… it’s totally different. There’s the physical capacity, there’s the physical piece, there’s the emotional piece, and there’s the energetic piece…it’s a piece that is on the plate of, I haven’t just said, “Well forget it we’ll never cross that bridge.” There’s a bridge there that I definitely want to figure out how to cross, it’s going to be interesting and difficult and challenging. It’s going to be challenging. So there’s been that loss. (female participant)

**Small story two: Feelings in the Modified Caregiver phase.** Moving further into the continuum of caregiving exacerbated feelings such as loneliness at times for some of the spouses. However, the Modified Caregiver phase was predominated by a change in perspective to focus on more positive feelings compared to the prior phases in the trajectory. Thus, the spouses also appeared to make some improvements in their feelings of loss and grief through the process of exploring feelings of acceptance.

**Feelings of loneliness were exacerbated intermittently.** Some of the spouses experienced intermittent periods of loneliness in this phase. Many of these feelings were associated with the number of years since the onset of the injury for their partners and because their partner’s personality and emotion had changed so significantly. Feeling lonely caused some spouses to temporarily resent their situation and subsequently the new roles
they have had to take on in their household. Overall, the spouses who experienced these feelings described them as intermittent because they were less frequent than in earlier phases of caregiving.

I still feel very lonely, I was feeling lonely yesterday and that whole caregiver thought came up and I thought I would do some reading on it …and it talked about how you have a very different person. Like my son says… it’s him but it’s not him. You know, it’s kind of that feeling… (Claire)

I hate it, I hate it. I wish it could be the way it was. I feel alone. My kids don’t get it, they see he’s here. Mothers and daughters have this (gestures tension, resistance), and fathers and daughters have this (gestures togetherness). It’s different, I know, I had that too with my parents. So if I lose it over something or I get frustrated, they always make a point of saying that it is not very nice of me because he can’t help it. (Anne)

Focusing on feeling positive motivates the well spouses and this is a shift from focusing on loss. Although the spouses continue to reflect on their feelings of loss and grief in this phase, they begin to acknowledge more positive emotions and experiences. On the positive side, the participants discussed the various factors that motivate them to continue moving forward in their relationship with their spouse and maintaining their family units. Many refer to love, loyalty and commitment as factors that initially propelled them into their relationships and as the factors that continue to foster their relationships. Other motivators include inner strength, faith, and fear of failure.
(So what motivates you to continue?) My life with him? I love him, and I really do love him. It’s the good times now, outweigh the bad times. They are so much better. If I was going to leave him it would have been a long time ago. (Lisa)

(What motivates you to continue?) I can’t imagine quitting and leaving. From being part of the association I belonged to I know 70 to 80% of marriages fall apart. We are lucky ours didn’t fall apart; I’ve never been one to just walk away from a situation. You know it happened you just continue and you do your best. I keep telling her, who the heck would have us anyway! (Doug)

Despite the losses and changes in the brain injured spouses, many of the well spouses appeared to be able to focus on positives. They described a process of identifying and engaging with the aspects of their spouses and relationships that have not changed in order to experience enhanced optimism and positivity. This process contributed to improved coping.

The process of striving for the feeling of acceptance. Those spouses, who are in the Modified Caregiver phase, spend time thinking about how they have come to accept their new life situation and their losses. Some participants report that it is important to find a positive rationale for accepting in order to move forward with their lives and to in order to feel like they were “living freely”, and as close to the way they once lived as possible. Acceptance is described as an adaptation process taken on by the well spouses. The well spouses seem to suggest that their acceptance must be a genuine and intentional action such as wanting to see the positives in their situation or feeling like they are moving forward; as opposed to a passive reaction where they simply stated that they had to accept their situation
because they did not have a choice. This process (intentionally accepting their situation) is a transition that appeared to be chosen and propelled by the well spouses, as opposed to having it thrust upon them. Perhaps this phenomenon was an action of taking control over one’s life in reaction to months or years of control that had been lost. Of note, for some of the well spouses, the adaptation process of acceptance began with a passive reaction (well spouses accepted because they had no choice) and then later lead to a more proactive choice to become more accepting:

Yah, it sort of becomes a routine. After awhile, it’s just part of what you do. You adapt, I’m a tough guy, I’ve been through tough times in life, with my son and that, I work…I thought I was going to go under, and I woke up one day and said “Nope” and put my nose to the grindstone and kept going, it’s not going to beat me. You work hard; you get out of life, for work or whatever…what you put into it. My brother in-law for example, he didn’t give a shit about this or that or anybody and now what does he have, he doesn’t have anybody. So if that’s your attitude. You can’t expect the world to owe you anything; you get what you put into it. You play with the cards you are dealt and that’s just the way, you can’t do anything about that, that’s the way it is, that’s reality. So what else are you going to do, you accept it. (Kyle)

C’est la vie, que serrai! I can’t get angry, I’m long past the “Why me?” stage, in fact I never really went through that. Maybe that’s just part of my personality that I never knew existed. I just accepted… “Ok yah this stinks but what the hell are you going to do?” So that’s the attitude I’ve had all along. So it’s not bothering me that this is how
it’s going to be. You look at the positives, as I said, it’s not worse it’s different.

That’s my life, maybe that’s a coping mechanism. (Mike)

Some participants discussed the ways they moved toward achieving acceptance:

It’s always been easy that way, accepting what it is (the situation), its part of the
philosophy, and because of that it is a lot easier than it could be. I imagine that a lot
of other people struggle much more (with this situation). (So the hardest part was the
not knowing?) Right because you can’t accept something that you don’t know what it
is. Once you know what it is, you can accept it the way it is. So I can cope and get
through and life is still going to be good. It’s nothing horrible at all. But for her yes
there are some intimacy changes for sure, the closeness, the oneness, the talking about
the future is gone…but when you roll it all into one, it is all good. (Bill)

So I was struggling with hanging on to the hope and thinking that’s not us. But after
some time went on, and I would go to the group and I would think to myself, I am
swimming against the current, against the tide…you know, that life is gone. I now
have to pool all my resources and figure out how to move forward for both him and
me…But I think once you get to the acceptance of…that life is gone… it gets
somewhat easier to start to deal with “How do I now create a future now from what I
have?” It’s like the process of the Phoenix; you know the bird that burns itself out.
I’m ok if…I’m really working at accepting where my life is at. I think going to the
group really helped me in the sense that I was hanging on to and fighting for
something that was never going to happen again and at least it helped me see that
people do survive mentally, and I’m really looking at accepting where we are and what happened. (Claire)

The other struggle is also accepting the imperfections that you have to live with, in terms of everything…your family life…imperfections…they come into every area…your relationships, you set the table…everything that you do is not the way it was or the way you would like it to be, even if it wasn’t perfect before. Everyone hopes to have the perfect house…the perfect whatever, so realizing that life is not about perfection but is about enjoying what you do have. (Inga)

After the initial passive reaction, they then move to a more purposeful action choice such as focusing on the positives and engaging in moving forward in a positive manner.

Acceptance, it’s tough. (Do you feel like you’ve accepted things?) Begrudgingly yah. (How do you think you came to that place to be able to accept?) I tried not to give in…like I tried not to just say, “This is my life,” I tried to better our relationship, and I still am trying to better our relationship, to accept it. I don’t want to be the martyr…I try to search for the positives, sometimes…not now as much as before, the negatives outweigh the positives…a lot. (Lisa)

He loves the kids, he loves when they are here. He brightens like a light bulb. They bring so much joy to him. They’ve come along in the last five years, so it’s all new and fun to him. It’s been a lot of fun, we might have had one bad hurdle to get over, but the last five years have been a lot of family joy. If you can think of the positives, they outweigh the negatives. So that’s the spin you want to put on it because it makes
it happier and easier to enjoy. If I had to live in the scenario of him being sick, and the daily routine or the daily grind of what I have to do, there’s no frickin way…I’d go crazy. So, I think about when I get to see him, or when I come home, we take the dogs out. (Nina)

I’m a better person, I appreciate him way more. I’m not as petty, little things are just little things. I’m a better person; I think I am more generous. I am able to love him better. I think before…I can’t imagine reasons for being unhappy before but I had a litany of things to complain about. He doesn’t even realize this, but he’s taught me more in the last three and half years about love…a different kind of love. I think I’ve understood what he’s been trying to share with me or trying to get me to understand beforehand. I think I understand what he was trying to…what his complaint about me was…that I was too…he never used the word petty but…I think I’m just more accepting. I’m way more accepting and I’m way more appreciative. I think about two years ago, I started coming to a place of knowing that whatever happens from here on in, we will be fine, absolutely fine, and really feeling that. Really trusting that and really knowing that. (Olive)

In order to work toward acceptance, the participants begin to focus on the positive outcomes of their spouse’s brain injuries. Some participants noted that they were eventually able to identify the changes in their spouse’s personality or demeanor which was positive.
(Have any positives come out of this?) Since his accident he’s social, he’s more social, he laughs way more than he used to. He’s more fun to be around… I married him, that’s a positive. He never wanted to get married; I went into the relationship knowing that he never wanted to get married. It was something that he just didn’t believe in. (Lisa)

If I had to sum up the pros and cons of what’s happened to him, the pros are: we ended up with the best person that you could ever want in your life. The cons were that it had to happen like that. (Nina)

That is one of the good things about Beverly, like it is sad that she has this short term memory problem but on the other hand…she’s always been into meditation, she’s been to abroad a few times… she’s been part of this group that is connected to a number of groups worldwide. She had spoken to groups of 100 to 1000 people about this philosophy. My point is, that it is all about living in the present and not being tied down (to future and past thoughts) so she’s here all of the time, which was what she was striving for before. She couldn’t plan an evil thought past the point of coming up behind me and staring at me. Anything that happens in the past is all gone, even if I tried to get her back into meditation, she’d probably be in a wonderful spot, it’s like she’s grown her innocence in one way, because she is so much like a child. (Bill)

Small story three: Supports in the Modified caregiver phase. More balanced interaction with supports was a theme that emerged from the small story regarding supports in the Modified phase. The well spouses’ interactions with supports were more balanced in
their dispersion across both the social and professional types of support. The well spouses engaged more successfully with social supports and they even began to recognize the potential for support existing within their own nuclear family units. They also found more productive and suitable professional supports in the community. It is not surprising that they were eventually able to identify better professional supports after several years of trial and error. This lengthy process suggests that there are improvements to be made in education and access to ABI community services.

*Reaching out again to family and friends for support helps to promote independence in the brain injured spouse.* The spouses discussed the successful strategies they discovered that helped to promote independence in the brain injured spouses. They re-engaged with family and friends to help the brain injured spouses step back out into their communities. More independence in the brain injured spouse translated into less stress and less need for support for the well spouse. On successful attempts at achieving independence:

As soon as he got his independence, he was 100 times better. He travelled a lot with his work and before his work, and now he travels with his friend from the group he attends. I’m hesitant about all of this travel because both of them are brain injured; it’s like the blind leading the blind. If I said no, and argued with him that he couldn’t go, I wouldn’t get anywhere. But it’s worked out well; they’ve done several trips so far. (Lisa)

I think a lot of that during the first couple years was simply because he didn’t like to be left alone. I was just the… “You have to be alone, you have to be independent” but we were always connected. If he’s not doing anything, I will say, “Ok you have to
drive me to work and then take the dogs to the park so they can go and have fun.”
That’s taken a long time, it took almost two years to get him out of our
neighbourhood, and that was great, that was great the first day he did that. The first
day he did that he rode his bike with my nephew and went down to the bank and got
himself Wendy’s and the second time he did it by himself. The GPS has been a
fantastic tool for him, and he has it in the car and he has one on his person. So he
knows to hit back home, and then he’s home again…That’s what I want to work on,
that’s what I need to be continuously working on, that is to make sure that he is able
to think for himself. He says, “What should I do?” and I say, “What do you think you
should be doing today?” and he says, “I don’t know” and I say, “Well don’t give me
the I don’t know because you get that from a nine year old, I don’t want that from
you, I want you to be able to say I am going to do this this, this, and this.” He works
great off a list, give him a list and he can do it, he might not finish it some days, and
other days you give him a list and he just doesn’t want to do it. (Nina)

**Connecting with community supports proves to provide opportunities for**

*meaningful activities for the brain injured spouses.* The spouses eventually found
professionals in the community who had appropriate skills for enhancing meaningful
activities for the brain injured spouses. On activities that they have discovered were
meaningful:

There is something that Mary has started doing, and this has been with Dr. M’s help,
Mary has spoken to groups…she spoke to the support group for brain injured
individuals and she spoke to Dr. M’s class. She has told her story to the newspaper;
she spoke at the support group at the rehab hospital, and other various groups. I
haven’t gone to many of those talks, but I went to one and it was great the way that Mary presented her story. She presented it as a series of vignettes. Each vignette kind of had a title, like, I lost the car, I want my license back …there was a realization that putting the vignettes on paper and starting a little book…So that’s what I want to do with Mary (next), get a book published. That’s a project, that’s something we can move toward. (Mike)

He goes and does volunteering just down the street, so he walks down… He cleans up… he washes… he hands them off… And it’s great because it’s a friend of ours and she has informed her customers about what Nick is all about…and he knows exactly what to look for. So I can’t be more thankful, that I’ve got somebody in our corner like that. To be willing to make him feel like he’s worthy in society, and not make him feel like he doesn’t belong out there. It’s nice, it’s nice for me and it’s nice for him, because it gives him a sense of independence and a sense of manhood. That’s one thing we’ve all tried not to let happen is to take any of that away. (Nina)

I’m paying for a class, like yesterday… he goes there from 9:00 to 12:00. He’s gone to three classes and then the rest of that day he was initiating full sentence responses to me when I just make some comment about what’s going on in the TV news. Normally, if I make that comment, he doesn’t say anything, he doesn’t chip in, he used to all of the time (pre injury), but last night he was chipping in. When I came home from work, he had put all of the dinner away, he had done everything with Owen. It was all day yesterday and this has been consistent after art class. On those
days there is more speech, there is more going on in his head, he’s more present, he’s
more alert. He took the dog out for a walk. I said, “Oh the dog hasn’t been out for a
walk in a few nights” so he said, “Oh, I’ll do that after I finish the dishes,” and he did.
(Olive)

Supporting each other by interacting more often within the nuclear family. Some
spouses noted positive changes in their family unit and the changes in the way their families
spent time together. Coming together as a family to complete tasks and navigate new
household roles was noted to reduce stress and foster happiness in the well spouses. Perhaps
the families’ ability to adjust to living in the moment (stemming from the Embryonic Phase)
allows for a shift in appreciation in the type of time and activities spent together.

(Going back to your experience, has there been anything positive that you’ve drawn
from your experience with Carl’s illness?) My resilience, that we as a family, my
immediate family, we’ve gone through a lot, we’ve been churned through a sausage
machine and we’re coming together. The positive part of it is, that we have survived,
it has been at a huge cost to us, you know, physically, psychologically,
emotionally…but you know we’ve survived and we are looking at…I can’t say we’ve
embraced our new life, but we are looking at how do we embrace our new life.
(Claire)

We never used to take the time to sit down together to have a family dinner, now we
have dinner together all of the time. Of course, nobody would have wanted this but
we’re ok. Not that I wanted it to happen for this reason but my son has a lot more respect for me now; not that he didn’t before (laughs). (Elaine)

Because Isaac’s been at home, we have lots of family time. We watch movies, go for walks, go to the park, we’ve been going for picnics every weekend. So it’s been good for the family actually. More time together than ever before. Since mommy’s the only driver…when you are not pressured to go out all of the time, you kind of find yourself, you know you do stuff together at home. We painted my son’s room together last week, which we haven’t done in ten years. Doing stuff together really builds everyone up and they enjoy it. We have time to just sit around and chat, there’s no pressure from work or outside commitments, besides our prayer group. (Inga)

**Supporting each other by interacting as a couple.** The participants, who were fully engaged in the Modified Caregiver phase, discussed the ways that they like to spend time with their spouse and the new activities that they have discovered and enjoyed together. Some describe their time together as new opportunities while other reflected on maintaining old activities that they enjoyed. The discussions revealed that doing things together propels the couple forward and helps maintain their positive outlook. Most importantly doing things together allows for a return to old roles in the relationship and/or for creating more balanced new roles.

I’ve found that we do more stuff together, more now than we ever did before which is interesting. I love to ski, I taught skiing, our kids could ski before they walked. Mary was always there, she hasn’t skied since the trauma. She might try it this year. So we’ve taken up snow shoeing, now I’ll still go out skiing, I have to that’s just my way
of dealing with life, I don’t do it very well but what the hell…but I quite enjoy going out snowshoeing with Mary. We never would have done that pre trauma. We just wouldn’t have thought of snow shoeing. (Mike)

You just…you live in the happy. We never pass up anything new to do. In fact, I’ve finally got him convinced to take a dance class because I’ve always wanted to learn how to dance. Finally we just got that accomplished. We watch our grandson’s sports; I try not to miss any family functions with Nick’s mom and brother, and their kids. (Nina)

Luckily we like similar things, we both like garage sales. Often we’ll go here and there on the weekend. We both like to walk so we’ll go walking…most weeks we’ll go three to four times per week and go for an hour to two hours. Not too far from where we live there is a nice park with a creek it is a nice walk. We have a swimming pool in our condominium so we’ll go off and do that. (Doug)

Although the spouses continued to feel loss and less continuous burden as a caregiver in this phase, they ultimately tried to modify those changes in an attempt to create a life that was more acceptable. During the Modified Phase, the well spouses increasingly focused on positive elements and things within their control such as spending time together. As the participants moved toward accepting their situations, they started to develop a way of thinking about themselves in yet another new role for their spouse, not a “caregiving” role, but rather, more of a partnership role. This new type of partnership however was inherently different than their partnership prior to the brain injury onset.
CHAPTER EIGHT

RESULTS

All Phases of the Caregiving Trajectory: Strategies, Methods and Styles for Coping

Overall, the participants engaged in various types of coping styles throughout the three phases of the caregiving trajectory. They reported using problem focused coping techniques where they adapted their behavior to adapt to problems. They used emotion-focused coping styles where they tried to release emotions, engage in self-care, or access supports. All of the participants were found to have engaged in appraisal based coping where they adjusted their thinking in order to better deal with their new life situations. Although, these themes have already been identified in various forms in the caregiving trajectory, they were discussed in relation to stressors, feelings and supports. Explaining these results in the context of coping is also important for understanding the relationship between these themes and movement through role transitions, and this process will be clarified in the discussion.

Problem Focused Coping

Several of the participants discussed the various problem-based skills they developed to cope with the changes in their spouse. Interestingly, the male spouses discussed problem focused coping skills more frequently than other types of coping mechanisms compared to the women. It should be cautioned that this should not be interpreted that more men used problem focused coping, however, it was apparent, that this type of coping was salient to them and thus influenced their experience enough that they felt compelled to discuss it more often during the interviews.
The well spouses discussed the skills they developed to diverse emotionally charged events and to support their spouses’ memory. Of note, all of the participants in the study had a spouse who was attending neuropsychological memory rehabilitation, thus, by default all were engaging in accessing problem based coping in order to find ways to support their spouses’ memory.

On developing the skill of “leaving a situation” to take advantage of immediate memory problems in order to diffuse an emotionally charged interaction:

With her, because of her short-term memory…like maybe she’s mad at you because you want her to get ready to go somewhere and she doesn’t want to go…you just walk out of the room and come back in and readdress it, and it’s like it’s all forgotten. And that’s what it is like with her. Before, I didn’t know that, so there was all this struggling where I would be at her saying, “Come on let’s go, let’s go.” But now there’s this relief because I can leave and come back calm, and create a calm atmosphere for her and she will cooperate and everything is good. *(Tell me about how you figured out to leave the room and come back?)* Trial and error, but it didn’t take much because her short-term memory is so bad. I mean I probably got taught it on some other little thing, but you know I picked up on it, it didn’t seem that hard. It took a lot of stress out of those situations; it was like beating my head against a wall. Now I can just come out and go back in and it is so much better…and she has completely erased it, so you are coming in fresh and she is fresh too, there’s no baggage or anything. *(Bill)*
(What do you do if you get frustrated?) Walk away. (Will she forget?) Oh yah, it’s like it never happened. I’ll go out for a couple hours, go out on my motorcycle, go see my buddy or whatever. (Kyle)

The well spouses had to learn to interact with their spouse differently in order to cope. Some reported that they developed skills such as listening and/or calmly listening. On developing new interpersonal skills to help spouse work through the brain injured spouses’ emotional dysregulation:

(Do you think you’ve developed any new coping skills?) Yah, I did…the capacity to listen. That was necessary because if you don’t listen things just get worse. So that was one coping skill. I didn’t adjust…I didn’t have to do things that I didn’t do pre trauma, like drinking or taking drugs, take up a sport I hadn’t done before, didn’t do that. Maybe I’m just lucky. Mary has her disabilities but they’re not so profound that I’ve had to shift gears to continue to function. (Mike)

(What did you do if she was angry?) I just try to let it go because if I respond back it gets worse. In my mind I don’t know what could happen with her, I don’t know what could go wrong in her mind, so you just leave it, back off. (How did you know to back off?) Just seeing the signs of aggressiveness that she demonstrates and knowing that she doesn’t know…thinking well she could pick up a knife, you don’t know what she is capable of because it is not her so I just learned to let it go. (Frank)

Often, the well spouses had to develop methods for supporting their spouses’ memory. One method that they all had in common was enrolling their spouse in a program
for neuropsychological rehabilitation of memory. In this program, the brain injured spouses were trained to use Smartphone technology to support their limitations in short term memory. The well spouses also developed their own strategies for compensating for memory problems. On developing other compensatory strategies to support spouse’s memory:

Well I had a friend who had kids and I asked her for some ideas because I had to get him to take his meds and all of that. She said, “Get a backpack, and what he needs just put it in his backpack,” so when he goes out he’d have everything that he needs. So that’s what I did and to this day he takes that backpack everywhere. His blue one just wore out it was the first one. You know that helped a lot, I don’t know why but it just did. He carries it everywhere, whenever he goes out. (Lisa)

**Emotion Focused Coping**

Above it was discussed that the participants developed new problem-based interpersonal skills such as self-control in order to deal with their spouse’s emotional dysregulation. Emotion focused coping strategies were also discussed and various smaller stories emerged out of the story of coping for these spouses. Emotion focused coping techniques were aimed at addressing the spouses’ emotional issues.

**Exercising self-control.** The participants also discussed exercising self-control as an emotion focused coping strategy to deal with situations not directly related to their spouse’s memory or behavior problems. Thus this type of coping was emotionally focused because it was not focused on developing a particular skill but rather utilizing a strategy to deal with their own feelings when confronted with various situations.
On withdrawing opinions in social and interpersonal relationships; and containing emotions:

*(How does it affect your ability to connect with friends and family, when you get the sense they don’t understand your experience?)* I guess it depends on the kind of person you are, I don’t want to be the whiner so you just let it go. It usually makes me say even less. You know, I’ve had enough conflict, so I can’t afford to offend them. *(So you withdraw?)* Yes, you pull back, you don’t say anything. You give in easier because you just want to keep the peace. You can’t afford to offend somebody that you might need to drive them somewhere or come help you out. You don’t say anything. *(Anne)*

But you know what, I can’t let that bother me anymore and I’ve chosen not to let it bother me because all of that negative energy makes me tired. It was draining me more than I was already drained. You have to learn to live with it. *(So you have to learn to live with it because the negativity becomes too much?)* Right. I mean what are you going to do, call people and say where the hell are you? No, I wouldn’t do that. Carl’s sister has done that with them (his brothers), called them and asked them to take him out. But I’m not going to do that with them, I need my energy for other things. If you can’t understand that your brother needs some of your time, well you’re not children. *(Claire)*

I think for me, my emotional states have fluctuated, in there it has been a roller coaster… that I’ve tried to stay off. Certainly I knew at first that Oscar’s health was
the roller coaster and I knew if I got on it, the highs and lows, that I would be of no use. So I think at times, I have realized that I’ve been getting tossed all around, allowing myself to get…to be reactive. (Olive)

**Seeking out, inviting and allowing for sources of social and emotional support.**

Although, seeking out support could be considered to be a problem focused coping strategy because of the skills that could be learned. It is included in the emotionally focused coping section to exemplify the impact that support has on personal emotions and thoughts such as increased happiness/satisfaction, and internal locus of control. The spouses discussed various sources of support in their lives. As discussed earlier in the phases of the caregiving trajectory, they often relied on family:

I’ve been lucky my three brothers have been pretty supportive. If I need something, they’ll come down and help out and they feel like they’re doing it because Al helped them. Al worked on their cars and now they don’t mind helping Al. They are pretty good that way, but they’re not living the life so they don’t get it. (Anne)

Nothing has really changed in my family, and well my parents have passed away. My brother and sister, we had a good relationship before this started and I think it has become stronger since. My brother is a single father so we don’t see him as often but he calls all of the time and will come help if I ask. My sister moved closer to me, she doesn’t have children…they’re very much a part of our life. My sister was an amazing support while Carl was sick; she took time off of work and did shifts with me at the hospital, pretty much every day. His sister has been really good too, she
doesn’t live too far and she committed one day a week to take him out too in the beginning. (Claire)

My family has been very supportive, my brother and others too. Francesca is very close to one of my brothers, they were close before and now they are closer. He realizes too that if she doesn’t call there is something wrong with her like she may not be feeling well. So he calls her and says, “What’s wrong, why haven’t you called?” They’ve been very supportive. Anyone in my family, if I needed support they would be there. (Frank)

They relied on friends for support:

One friend has been a friend of ours since high school, we’ve always stayed friends, him and his wife, and Henry and I. You kind of float back and forth over the years, but, when Henry got sick, he just has been unbelievable. Every day he calls or comes, by, every day. At the hospital it was the same thing. The only time he didn’t was when he was at the rehab hospital, but he would come down once a week and he made it a point to go midweek, because he knew it was hard for Henry to get through the week, because we would bring him home Friday and take him back Sunday night. (Heather)

Anything from financial to food, I had a bunch of friends who drive in from Iskar to bring me food once a week. They do a little pool, where each family once a week,
brings food for us. Last year for about six months, they did that for us. They help look after the kids, and they come and do stuff in the house, that needs to be done. Lots of families pray for us. (Inga)

I knew that I had to eat and call on people to help. So I guess as an individual… I had a lot of people comment on how amazingly well I was handling it, but I was being resourceful, I was calling on folks to help. (Olive)

They sought out professionals individually for support:

It wasn’t until I met up with the social worker… everyone kept telling me you need to get counseling you need to get help. Well that first year there was no time for me, it was a whirlwind. Even when he came home, he was in a complete daze. So the first social worker I worked with was great but her primary objective was getting him (Carl) the right care. So we had a couple of sessions, and they were emotionally purging for me. The social worker who worked with me at the rehab hospital helped me unravel what I was about to really embark on. You know after a year, I was thinking it was nearly over, but I was still just beginning… Well I’ve been seeing a psychologist for a year, shortly after that breakdown. I started seeing a psychotherapist and then went on to see a psychologist and I see her regularly still. My family doctor has been really terrific in providing support and has never once said there’s nothing wrong with you, you just need to move on… who understood. So that’s been a big help. (Claire)
(You mentioned that you saw a therapist, is there anything else that you have done to help yourself cope?) Well I saw more than one therapist. I talked to my family doctor. I had gone to the brain injury association meetings. Sometimes listening to other people’s problems helps. I’ve come here to the spouses group. (Lisa)

They sought out help through support groups:

I belonged to a support group at a brain injury group for five or six years and it sort of dissolved but it was very helpful because you had other people who were having similar stories. You also learning about what you should be doing or what programs were available in the community. So that was helpful. (Doug)

(Do you recall what kind of coping mechanisms you developed in the past and did they change over time?) Well I did go to the doctor to ask for help, so I used medication to help. I went to Al’s family doctor and asked if he could be a central person to help me navigate this situation and he was as useless as useless can be. I don’t think I coped that well, I think I put on a good act outside of it all. Sometimes I know I don’t cope well because my kids get mad and say mom I am not going to talk to you if you have tears coming down your face. So, I don’t know if I coped that well. I try not to let him or the kids see when I am feeling bad. I don’t know what else I do to cope. The support group and having made a connection with somebody. We go out for coffee once and awhile and we can really talk, not the surface talk I do with my friends now. You can complain and that kind of thing. (Anne)
**Attempting to develop skills in self-care.** Self-care is an activity that is recognized as important for improving one’s emotional well-being and subsequent physical health, often resulting as a function of reducing stressors in one’s environment. All of the participants discussed their attempts at self-care whether these attempts were successful or not. Some were more successful than others in maintaining personal activities and/or finding new things to do for themselves. Many struggled with finding the time to do things for themselves while others struggled with separating themselves from their spouse. For some participants, self-care felt like an unachievable activity that was too complex due to the many factors that interfered with the actual opportunities for self-care.

Even when I delegate things to Al, I still have to follow him around because of his memory, you know... if he gets halfway through and doesn’t know where he left off or what he was doing, I will have to prompt him. That takes away from the time you were going to do something else. You spend your time following them around; you’re doing everything for everyone else. There isn’t a lot of you time. (Anne)

Your whole self care goes out the window. I do really try to make time for myself but…I do really try. (What kinds of things do you do?) Well this week I’m going for a manicure pedicure. This Saturday I’m going to a good friends house for a bridal shower and I’m going, everything else can just stop, I don’t care I’m going. Everyone else will have to be stuck at home because we only have one car well too bad, because I’m stuck all of the time. (Claire)
Some spouses indicated that a significant amount of time elapsed post injury before they even thought of their own needs for self care. The following excerpts describe discussion regarding the amount of time it took to get to considering self-care:

(What about in the beginning, were you able to take time for yourself?) Oh god no.
(How long did it take to start being able to do things for yourself?) Well it seemed like forever, it was a long time before I thought of myself, but we got through that.
(Lisa)

My relationships have become…actually things are becoming, things are moving on to the next stage. I did go camping with a friend and her son and Owen and it was really nice to have that and Oscar stayed at home by himself. I went on a canoe trip with a friend and Oscar stayed at home and it was really nice. We’re three and a half years in (to the brain injury). (So now is the time where you are able to start doing those kinds of things?) Yah. (Olive)

I just started up baseball again this year because the girls can take on a little bit of responsibility now or I can drop her off at her sister’s house. I’m starting to get out a bit more. I would like to start hockey up again this year, and I would like to snowmobile race a lot more this year than I did last year, which will take me out and around more. I hope to go with my buddies because these events are in several places in the states. I would take Beverly to a few too, we can make a family vacation out of it, get a hotel room and they can stay and swim etc. while I race. (Bill)
The participants described the types of attempts at self-care that were beneficial and enjoyable:

(*How do you take time for yourself, do you do things on your own?*) I have never been good at that and I have never found a way. The only thing I do now that is that time for myself is that we got a dog when Al got sick, and the dog became my responsibility, I take him for walks. When Al first got sick and I would take a walk just to get away from it, everybody would want to know where I had been and if everything is ok. Now, the dog needs to be walked. So after dinner, as much as I don’t want to walk that dog, I get half way down the street and I feel better. (Anne)

(*What kinds of things do you do for yourself?*) I go get my nails done, I still do my massage therapy, I try for once a month. I go out for coffee once a month with Norma. We do once a month mommy daughter days or nights. I’ve been socializing more with friends that I have been away from for a long time, planning vacations. We did do, for a long time, that we are not doing right now, date nights…but they got pushed to the way side for whatever reason. That’s about it, the rest is for us, family, a lot of time with my grandchild and grand niece, those are fun times. (Nina)

That hour, that everyone is sleeping, when I get up early in the morning, is my time basically. Whatever I do then is more relaxing. (*What kinds of things do you do for yourself?*) I don’t do much, except stuff around the house. I honestly don’t do much; I’ll go for walks at night. We used to try to go together but it doesn’t work because
she’ll go at a very slow pace. I have a much quicker pace so I’ll do it by myself.

(Frank)

Overall it appears that the spouses needed time to focus on the care of their ill spouse before engaging in their own self care. Once they felt ready to engage in their own self care they needed opportunities to engage in relaxing and enjoyable activities. It appears that these activities were individually focused based on the interests of the participants. They reported needing support from family members, friends, or community services in order to engage in self care because they found it more relaxing to leave their spouse under supervision as opposed to leaving them alone and worrying while they were out.

**Escape and avoidance behaviours were successful emotionally focused coping techniques.** Escape and avoidance behaviours were described as successful emotionally focused coping techniques because the participants reportedly engaged in challenging productive and social activities as part of their escape/avoidance patterns. Returning to work emerged as a popular and successful avoidance method of coping, and this was previously discussed in the Immersed Caregiver phase because decisions about returning to work appeared to need to be addressed in that phase. Although the underlying connotation of the terms ‘escape’ and ‘avoidance’ typically would have a negative undertone, in the case of spouses of amnestic individuals, the implication emerged to be positive as this coping strategy appeared to benefit the well spouses in various ways (i.e. emotionally and financially).

*(What kinds of things have you done to work through this and cope?)* I guess work is one way to get away from everything, even though there is pressure there. There
are times when I go to work and it helps, I try not to think about things at home. I have a friend at work who has a son with Autism so I hear about her challenges; we talk, so that helps. (Frank)

Work has definitely been a huge pro to me with respect to his recovery. Because it still separated me and gave me the strength and gave me the focus…Work has always been, the more I have on my plate the more I can deal with it. (So keeping busy?)

Yah. I’m not one to sit still and I get bored very easily. So to be busy and to be constantly on the go is probably the best way for me to deal with something. Give me something to do and tell me to run with it and I am good to go. But tell me no it’s okay sit still and we’ll deal with it, I go, “No that’s not okay for me.” I like to be out there, and if I’m not in the house cleaning then I’m out there in the garden so that we have a nice home. I keep things planned as much as possible. If I could just get the paperwork done, things would be better, but there’s got to be something that’s not 100 per cent, but the laundry is done though! (Nina)

Going back to work was a big part of that…having the other focus to keep me going. I didn’t have time to fall apart. Well everyone has been, all the doctors have been very supportive and they have said what about you, how are you doing? I remember the one doctor from the rehab hospital, said…and I said I was going back to work…and he looked at me like that wasn’t a good idea…and I said, “Well I like work and I have friends at work…I’m not Heather Harp when I’m at work, the kids
don’t call me that, and not like when I’m at my kids school…when I go to work, I’m Heather Hickory Harp and I’m a different person, just me and I like that.” (Heather)

**Appraisal focused coping is a subset of emotion focused coping strategies.**

Appraisal focused coping techniques involve adjusting the way one thinks about events in their lives in order to cope. Ultimately, many of the participants had to adjust their thinking and expectations in relationships in order to better cope with their spouse’s post injury changes in behavior and cognition. They also learned to adjust the way they prioritized tasks at home and at work, and to change their perspective about things that were once important to them. On adjusting one’s perspective and learning ‘not to sweat the small stuff’:

*(Do you think you’ve had to develop any coping skills?)* Probably my letting things go. My friends at work joke around and say to me, “Let it go…let it go (gestures).” That’s probably the biggest thing. Now prioritizing and some things just aren’t important…Well that’s probably the biggest…being able to let things go. My hardwood floor is a mess, because we have two kids and two dogs and a pool and there’s water everywhere, and the dogs have gotten wet. Before, that would have had to be spotless. Now I think I don’t have to have that clean right now, which is a huge turn around for me, huge. It’s not a priority right now. (Heather)

*(Do you think you approach life differently now that this has happened?)* Yah, definitely, I don’t sweat the small stuff anymore. I don’t sweat the details. At least I don’t as much as I did. *(So it’s bigger picture?)* You just don’t sweat the details, I don’t ignore the details, but if things aren’t exactly how they should be I don’t really sweat them the same way I did before. I’m talking about the day to day stuff; if
papers aren’t put away I don’t worry about it. If the cars aren’t clean, I’m fastidious with my cars…not so much anymore. There are more important things to deal with. *(So does that approach reduce stress in your life?)* Yes, to a large extent it has. 

*(Mike)*

On Thursday night we were supposed to be going to a screening of a movie. Nick had it in his palm but forgot to put it on the calendar, and forgot to tell me before I went to work. Will it ever be perfect, well I’m not perfect so I can’t ever expect him to be…so we do the best we can and sometimes there’s a hiccups. So you do the best you can. 

*(Nina)*

Some participants discussed the phenomenon of adjusting perspective about their situation. This appeared to refer to changing life choices on a day to day level as well as involving a transition into an overall more optimistic perspective:

I had to face reality, but it was really hard though. You cannot imagine your life being turned on its head like that. When we left our home country and came here to have a better life and raise our family and then suddenly that’s a dream and this is a reality…now all of that was a dream, the realities that you face now, are completely different. I had to keep my wits about me. I had no luxury for feeling sorry for myself or in any way cutting slack for myself. *(Inga)*
Enjoying it (life), to not put off. I would have never have gone to the Netherlands. People have this tendency to help and to make it happen for you. When you’ve got a lot of friends and back up it can happen…We’ve been to the Air Canada Centre. You know my friends call it the bucket list, I don’t call it a bucket list, it’s just things you want to do in life, you just go and do them. You don’t say you’ll do it tomorrow because tomorrow might not be there. Whether it’s for him or whether it’s for me, it just might not be there. (So would you say you have a different perspective on life?) Yah, I try not to work as much. But you’ve got to work to make a living. You’ve got to keep going to live the life you want to live and enjoy it. I don’t want to not enjoy it. (Nina)

I just saw it on a daily basis, so I realized this was the way it was going to be. So you adjust yourself accordingly, because there is nothing you can do about it. (Gertrude)

Changing perspective also included having a new understanding of others and the complexities of interpersonal relationships. This cognitive appraisal style of coping involved making decisions about severing relationships or building new relationships with unexpected individuals:

And other people, the ones who disappear; they can’t handle what they see so they just disappear. You feel resentment for that too and you don’t want to resent people because you’ve had enough of resenting people. You want to be forgiving because you never know what else is going on behind closed doors, you don’t know what else
they’ve got going on, I’ve certainly learned that. You know, friends change, family members they change too. (Anne)

Well we just concentrated on those people who were there for us in a positive and supportive way. It was interesting now that we have found out after the fact that the folks that we have focused on …well the folks that we didn’t focus on prior to the trauma, they’ve become part of our lives. So that’s how we have coped basically. (Mike)

*Positive re-appraisal was an appraisal focused coping style that some participants aspired to achieve.* As was discussed in the Modified Caregiver phase chapter, many of the participants utilized positive reappraisal as a coping strategy. Thus, they tried to think of various situations or their overall situation in a more positive perspective. This type of thinking was predominant in the Modified Caregiver phase however; it was not entirely exclusive to that phase because some spouses appeared to move back and forth between the Immersed and Modified phases. Focusing more on mastery of this skill however, helped to maintain the Modified phase. Some participants acknowledged that they very deliberately changed their thinking to a more positive skew in order to cope; others discussed it as a more subliminal process:

I had that faith and that hope that ‘this’ was a stage and in another month we would be in another place and thankfully we were. At least I knew Oscar was recovering, it wasn’t a progressive disease like Alzheimer’s. I said to myself, “This is about recovery, this is an upward path, as slow as it is, it is an upward path.” So that kept me going. (Olive)
I rely a lot on what I learned in my own coaching program. You know that I am the only one who can make a difference in pulling us out of this and whatever direction we are going to go. You know if I stagnate that’s not good for me, for Carl, or the kids. So I’m really working hard at accepting life has changed, he’s not who he used to be but he’s a lot better. At the risk of sounding cliché, I’m trying to make the best of where we are I’m really working at that. (Claire)

So I look at it as his time with the family and enjoy it when it lasts. Hopefully, there will be a time when he will be able to go back and that kind of pressure will be back upon us. We don’t know when that day will come and of course they tell us that it will probably never happen…but you know what we have to hope and we have to keep going… Sometimes I get upset about what Isaac cannot do or does not want to do but I thank God for giving me the strength and the wits to be able to do it. I mean I embrace it instead of resenting it, because as long as I have energy and my limbs and hands and there’s…why waste an opportunity to do something I can do…I might feel bad that someone else is now doing it. It was amazing, when you’ve been through that a few times you know if it has to work out it will and if it doesn’t work out its ok, there’s nothing you can do about it. So you might as well sit back and enjoy the rest of your life. (Inga)

Acceptance via positive re-appraisal. There were some thoughts expressed by the spouses that indicated they were moving toward accepting their situation. Feelings of
acceptance appeared to emerge out of implementing the positive re-appraisal coping strategy. Fifteen out of the fifteen spouses interviewed were able to adjust their thinking in a positive way and stated that they realized there are people who have much worse situations in their lives. This kind of thinking (“others have it worse”) helped the spouses to positively evaluate their situation and maintain motivation to keep going when things became difficult.

When she was in ICU at Kerman Hospital, one of the nurses told me she could have come out the other way, where everything makes her angry, so you have to look at the bright side, it could be a lot worse. Yah it can be annoying but if she was angry all of the time it would be pretty difficult dealing with something like that. (Kyle)

The one thing that my limited participation in these spousal programs did was illustrate just how lucky I am. Yes the trauma occurred, so that’s not very lucky, but the fact that Mary’s very high functioning is very critical…there’s some people out there who just can’t cope. The people involved in your program who really don’t have much capacity at all. So I really consider myself lucky, count my blessings. (Mike)

I think we got off lucky if you can call it that. I know of people who are far worse condition, financially, mentally, emotionally…who don’t have as much support as I do, and I wish that everybody could have what I feel I had. Some days I wish I could have more but you know, I’m glad about what I do have and what I have accomplished and where we are today in comparison, because it pales. (Nina)
Here, thinking that other people in the world have worse situations provided comfort to the participants. This positive reappraisal style of thinking largely contributed to the participant’s acceptance of their new life situation. This style of thinking is an effective form of coping because it helps the spouses move forward and make sense of the changes to their lives.
CHAPTER NINE

RESULTS SUMMARY

Summary of the Results: The Caregiving Trajectory a Three Phased Model

Before the discussion and conclusions are addressed, the findings regarding the phased model of role transitions in caregiving is summarized below in order to provide a more succinct view of the results reported to this point. This summary is intended to guide the reader through the pertinent points of the care trajectory without the interruption of the inserted quotes from the data. Also included and summarized are the stressors, feelings, and supports outlined in each phase. At the time of the study, none of the participants were in the Embryonic Phase, four participants were in the Immersed Phase and 11 participants were in the Modified Phase.

Phase One: The Embryonic Caregiver

During this phase everything was new to the spouses and this created a lot of uncertainty and subsequently feelings of anxiety. Te spouses had to navigate many new roles while dealing with feelings of loss and grief. Essentially, they were in a crisis situation. Many family members and friends reached out to provide support. This phase appeared to discontinue as spouses moved into the next phase of the trajectory.

Stressors in the Embryonic caregiver phase. The various ideas that were generated from the findings for this group of individuals during the Embryonic caregiver phase included: managing uncertainties and immediate medical decisions in the context of acute medical care, in-patient rehabilitation care, and the initial transition home from hospital (see Table 4). These situational stressors were global in nature where they described a very
encompassing scenario that involved many sub categories of stressors on a day by day basis. For example, navigating the acute health care system involved many sub category stressors such as: hearing bad news, thinking one’s spouse is going to die, navigating an unstable health condition, acquiring an accurate diagnosis, managing time between home and hospital, finding an appropriate care floor that can manage individuals who wander, having a tense interaction with a family member, and so on.

Table 4

Some Examples of Situational Stressors in the Embryonic Caregiver Phase

<table>
<thead>
<tr>
<th>Situational Stressors</th>
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<tbody>
<tr>
<td>1. Illness/injury onset and understanding the illness/injury itself</td>
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<tr>
<td>2. Navigating the Acute Care System</td>
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<tr>
<td>3. Navigating the Rehabilitation Hospital System</td>
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<tr>
<td>4. Learning how to effectively interact with the health care team</td>
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<tr>
<td>5. Understanding treatment modalities and medications</td>
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<tr>
<td>6. The brain injured individual comes home and chronic healthcare considerations arise</td>
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**Feelings in the Embryonic caregiver phase.** During this phase, the numerous and frequent role transitions resulted in feelings of uncertainty, stress, anxiety. Feeling prepared for some roles such as advocating helped to reduced feelings of stress and anxiety. Permanent changes to their spouses’ health initiated feelings of loss and grief that were eventually exacerbated over the subsequent phases of the caregiving trajectory as the spouses systematically learned and experienced the dramatic changes in their brain injured partners.

**Supports in the Embryonic caregiver phase.** With regard to social supports, many of the participants reported having adequate social support from family and friends during the onset of the illness and for the time in acute care and rehabilitation hospitals. Overall, the participants felt that there were not adequate professional community supports in place to assist with the new roles required of them once the brain injured spouse came home. Many
of the participants had to rely heavily on friends and family for support and assistance in this transition. For the most part however, the spouses tried to take on many of the roles on their own.

With regard to professional supports, many of the participants reported not knowing where to go to find information regarding brain injuries and brain injury services. They reported that advocacy, information, and general direction for next steps were lacking in acute care facilities. In community settings, they were unsure about what organizations were appropriate to contact for help. Consequently, the spouses indicated that they did not have enough information and professional support regarding what to expect when they arrived home from hospital with their spouse. They reported the acute care approach of giving spouses/families a list of services in various communities was not adequate. The message emerging from these findings has identified a gap where those providing the information about services were not giving enough specific details. Thus, the participants reported that they wanted information about services that would be very specific to their needs.

Role transitions in the Embryonic caregiver phase. In summary, some of the types of role transitions identified in the study in the Embryonic Caregiver Phase included: caregiver to an unwell spouse; advocate; information gatherer; help and support seeker; brain injury healthcare consumer and specialist; family pillar of support; not a worker or temporarily away from work; less immersed parent; and less focus on self (see Table 5). For some spouses, after discovering that there were few services that would be helpful to them, the spouses learned that they had to take on new and unwanted roles. Furthermore, being immersed in constant feelings of ambiguity created a significant amount of stress and subsequent role strain for the well spouses. Taking on tasks that involved incompatible
demands between roles such as being a wife and caregiver at the same time also resulted in role strain. Overall, role transitions wrought with underlying feelings of conflict and ambiguity left the spouses overwhelmed and sometimes feeling like they could not cope.

Table 5

Role Transitions in the Embryonic Caregiver Phase

<table>
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<tr>
<th>Role Transitions</th>
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<tbody>
<tr>
<td>1. Spouse of unwell partner</td>
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<tr>
<td>2. Advocate</td>
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<tr>
<td>3. Medical information specialist</td>
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<tr>
<td>4. Hospital system navigation specialist</td>
</tr>
<tr>
<td>5. Information gatherer; service seeker</td>
</tr>
<tr>
<td>6. No Longer a Worker, or Time away from work (unable to fulfill roles)</td>
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<tr>
<td>7. Different kind of parent (disruption to family unit, unable to fulfill roles)</td>
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<tr>
<td>8. Significantly reduced self focus</td>
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<tr>
<td>9. Emotional Pillar of Household</td>
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<td>10. Living in the moment</td>
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The specific skills learned by the spouses who participated in this study were: advocacy skills, healthcare management skills (including effective communication with healthcare professionals and keeping a log), information gathering skills, service identification and initiation skills, and adjustment skills. Some of the skills learned helped the spouses cope with the transition into their new roles. Many engaged in trial and error in order to adjust.

Feeling like one is living in the moment was the marker that was identified for transitioning into the Immersed phase. This phenomenon signaled the end of the Embryonic phase and involved focusing most activities of the family on the care and needs of the brain injured spouse. This transition coincided with a shift from reacting to numerous new crises related to the illness itself and acute care to reacting and managing various and new crises in the chronic care system. The spouses had developed some coping skills at the time of this
transition that helped their navigation of new but similar crises or changes in caregiving roles.

**Phase Two: The Immersed Caregiver**

In this phase, well spouses may have quit their job or returned to work, and their children may have been expected to provide significant support and help for the brain injured parent. The major changes identified in this phase included focusing on treatment at home and attending numerous appointments. During this time many of the well spouses realized that their most significant role change was realizing they were taking over all decision making and becoming responsible for managing the household.

**Stressors in the Immersed caregiver phase.** Many of the changes in the Immersed Caregiving phase caused new situational stressors for the spouses (see Table 6) in addition to the continued stressors stemming from the Embryonic Caregiving Phase.

Table 6

<table>
<thead>
<tr>
<th>Situational Stressors</th>
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<tbody>
<tr>
<td>1. Understanding the illness/injury ramifications</td>
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<tr>
<td>2. Navigating the chronic healthcare system and lack of services</td>
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<tr>
<td>3. Navigating appointments</td>
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<tr>
<td>4. Parenting issues</td>
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<tr>
<td>5. Household problems (fixing/replacing items)</td>
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<tr>
<td>6. Role overload; making new decisions</td>
</tr>
<tr>
<td>7. Financial Issues (including work decisions)</td>
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<tr>
<td>8. Changes in relationships</td>
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<tr>
<td>9. Recognizing cognitive changes and losses in spouse</td>
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**Feelings in the Immersed caregiver phase.** The participants discussed feeling guilty, frustrated, stressed, misunderstood, exhausted, sadness and loss, and burden. The
many role transitions experienced by the well spouses lead to the development and experiencing of many different feelings. Many of the spouses experienced feelings of exhaustion at some point in their caregiving journey and these feelings were most often related to role overload. Naturally, due to the numerous new roles that the spouses transitioned into, they experienced role overload and subsequent caregiver burden. Changes in relationships and reluctance to continue to ask for help deterred the spouses from continuing to seek out practical support from their community.

Loss and grief was associated with the many changes in the brain injured spouse. In the Immersed Caregiver Phase, the spouses began to recognize the long term losses in their spouses. These losses were not evident immediately after the injury as there were so many unknowns about the potential recovery for their spouse. The losses experienced by the brain injured spouse were related to loss in cognitive (memory, decision making, planning, multi-tasking) and physical function (walking, other aspects of mobility, physical strength and coordination, fine motor control, and sexual functioning). Although the individual spouses processed and coped with their feelings differently, various themes emerged regarding the ways that the feelings were interconnected with the roles within a marital relationship.

Supports in the Immersed caregiver phase. With the taking on of all of the new roles, changes in supports emerged as a theme in the findings. The participants noticed changes to the level of support offered from friends and family when the brain injured spouse returned home from hospital. When supports started to taper off they started to feel isolated and disconnected from their prior sense of community. The spouses themselves also contributed to their own isolation by purposefully reducing contact with some of their social supports. Thus, the participants went through a process of changes in relationships in this
phase. The findings suggested that outside others’ lack of understanding and empathy and difficulty seeing the changes in the brain injured individual were precursors to the deterioration of supports. Some experienced more role overload as they took on roles that supports were once taking care of for them. Here expectations of friends and family were not being met thus leading to feelings of frustration, sadness, and disappointment and ultimately causing changes in relationships. Concerns about continuing to burden family and friends with requests for help also contributed to the narrowing of social supports. With regard to professional supports, similar themes found in the Embryonic phase such as lack of information and services prevailed in the community.

**Role Transitions in the Immersed caregiver phase.** In addition to the role transitions experienced in the first phase of the trajectory, the spouses encountered new role transitions as they became more immersed in their caregiving role when their spouse returned home from the hospital. Some of these transitions included: household manager, ultimate decision maker, chronic health care navigator, recovery and care coordinator, single parent, social convener, financial resource provider and decision maker, worker or non-worker, and support seeker (see Table 7). The role transitions were accomplished while grieving many losses and dealing with the psychological distress associated with the transitions. Again, many skills needed to be developed in order to effectively carry out these new roles, and thus, spouses learned how to: deal with finances, deal with home maintenance, navigate homecare and outpatient appointments, find information about brain injury services, find information about disability subsidies, navigate changes in relationships, manage the needs of children alone, and identify the needs of their spouse.
Table 7

Some Examples of Role Transitions in the Immersed Caregiver Phase

<table>
<thead>
<tr>
<th>Role Transitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Spouse of a chronically unwell partner</td>
</tr>
<tr>
<td>2. Advocate</td>
</tr>
<tr>
<td>3. Medical information specialist</td>
</tr>
<tr>
<td>4. Chronic healthcare system navigation specialist</td>
</tr>
<tr>
<td>5. Information gatherer; service seeker</td>
</tr>
<tr>
<td>6. Becoming a worker or giving up being a worker</td>
</tr>
<tr>
<td>7. Single parent</td>
</tr>
<tr>
<td>8. Significantly reduced self focus</td>
</tr>
<tr>
<td>9. Emotional Pillar of Household</td>
</tr>
<tr>
<td>10. Ultimate decision maker</td>
</tr>
<tr>
<td>11. Household manager</td>
</tr>
<tr>
<td>12. Social convener, relationship navigator</td>
</tr>
<tr>
<td>13. Spouse motivator and fosterer of productivity</td>
</tr>
</tbody>
</table>

The data suggested that the well spouses developed a need for fostering independence in their brain injured spouses. Spouses may have arrived at this idea from different sources; some were experiencing role overload and began to re-enlist their spouse to help in order to reduce their load. Others recognized that establishing independence in the brain injured spouse helped to improve the recovery process as it engaged their thinking and sense of activation. The ways in which the well spouses helped their spouses to develop independence marked a role transition into the Modified Caregiver Phase. In this transition from the Immersed phase to the Modified phase, the well spouses were becoming much less reactive in their caregiving and more proactive. Thus, this transition coincided with a shift from reactive crisis oriented caregiving to more proactive and planning focused caregiving.

**Phase Three: The Modified Caregiver**

In the Modified Caregiver Phase, it emerged that the spouses made attempts to restore balance in their relationships with their partners by focusing more on finding opportunities
for independence for their spouse. Although the well spouses continued to feel loss and burden as a caregiver, they started to modify various role changes and transitions in order to form a life that was more acceptable and focused on positive elements. It emerged that many individuals did not want to consider them self a caregiver but would naturally rather considering themselves a partner once again to their spouse. Of note, not all participants had reached this phase in the caregiver trajectory because some were less than two years post injury. The findings suggested that many of the participants appeared to move back and forth between the immersed and modified caregiver phases and hence making short lived attempts at modifying their relationship with their brain injured spouse. Thus, it was not clear if all the caregivers reached a fully modified phase or if they remained in a state of constant transition between the immersed phase and modified phase. Overall, the Modified Caregiver Phase was a time where the well spouses were looking to restore balance to their marital relationship and to restore nuclear family function while instilling independence and meaning in their spouse’s life. Also, they took time to focus on their own health concerns. In moving forward the spouses began to focus on the positive aspects of their lives and doing things together with their spouse; being supports for each other while being better able to manage extraneous stressors.

**Stressors in the Modified caregiver phase.** The findings determined that during the modified caregiver phase the well spouses began to develop worries about their partner’s future health and potential for more health problems. The spouses worried about their own health and how problems with their own health might impact their children and brain injured spouse. These worries contributed to the well spouses’ role strain as they had taken on the responsibility for the functioning and future of the entire family unit.
Other stressors identified included finding ways to promote meaning and independence for the brain injured spouses. The spouses did achieve some success in alleviating this stressor by finding meaningful activities and developing opportunities for independence for their spouses. Some of the ways the well spouses made successful attempts at promoting independence were: asking their spouses to complete tasks on a list; encouraging them to attend appointments alone; encouraging decision making; encouraging spending time with friends; encouraging independent travel; and encouraging pursuing self interests.

Sexual intimacy concerns continued to be a stressor in this phase. It emerged that because the brain injured spouse was no longer focused on sexual intimacy, the well spouse was forced to carry the burden of this loss while still be “in charge” of deciding how or when to be intimate. Another significant issue arose related to sexual intimacy where some of the spouses discussed feeling very reluctant to engage in sexual intimacy because their brain injured spouse is more vulnerable and does not have the same sense of self.

Overall, there were new stressors that impacted the spouses during this phase (see Table 8). These stressors were connected to new and ongoing worries. Once the spouses reached this phase they did have more time to address their worries and perhaps that is why they emerged as a point of focus in the caregiving trajectory. Again, the stressors were mostly cumulative where new stressors emerged while many old stressors did not dissipate. Of note, the process of coping allowed the participants to temper some stressors through various strategies.
Table 8

Some Examples of Situational Stressors in the Modified Caregiver Phase

<table>
<thead>
<tr>
<th>Situational Stressors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Understanding the illness/injury ramifications</td>
</tr>
<tr>
<td>2. Navigating the chronic healthcare system and lack of services</td>
</tr>
<tr>
<td>3. Navigating appointments</td>
</tr>
<tr>
<td>4. Parenting</td>
</tr>
<tr>
<td>5. Household problems (fixing/Replacing items)</td>
</tr>
<tr>
<td>6. Role overload; making new decisions</td>
</tr>
<tr>
<td>7. Financial Issues (including work decisions)</td>
</tr>
<tr>
<td>8. Changes in relationships</td>
</tr>
<tr>
<td>9. Recognizing cognitive changes and losses in spouse</td>
</tr>
<tr>
<td>10. Changes in sexual intimacy have not been addressed adequately</td>
</tr>
<tr>
<td>11. Continued lack of independence in spouse</td>
</tr>
<tr>
<td>12. Worries about meaningful activity</td>
</tr>
<tr>
<td>13. Health concerns</td>
</tr>
<tr>
<td>14. Concerns for future</td>
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</table>

**Feelings in the Modified caregiver phase.** In this phase, the spouses focused more on positive aspects of their situation and they moved toward acceptance of their situation. The findings suggested that the spouses initially accept their situation passively, where they felt they had no choice and that they were doing what they should be doing for their spouse out of commitment. Later, and likely in the modified caregiver phase, the spouses chose to view their acceptance as a choice and as something that could be cognitively reframed in a positive light. They began to look at accepting their situation differently, where they chose to become actively involved in making their lives better by achieving more joy and balance and subsequently allowing them to rationalize or reconcile their losses and focus on the positives to move forward. The spouses noted that they felt motivated by positive feelings and this encouraged them to continue to focus on the positive.
**Supports in the Modified caregiver phase.** During this phase, the spouses reached out again to social support from family and friends. They enlisted support for caregiver relief and self care activities. The data suggested that effectively communicating one’s support needs and expectations to family and friends lead to increased chances of receiving support, however, this action did not preclude any of the participants from being occasionally disappointed in relationships with regard to having their support needs met. They reached out to community members for support to help engage their spouses in independent and meaningful activities. Successful meaningful activities included: giving talks about the experience of having a brain injury; volunteering for the heart and stroke foundation; volunteering at a workplace of interest (such as a kennel for pets); reading to school age children (or assisting a child’s teacher); and participating in a class of interest (such as art). The spouses also looked within their own nuclear family to feel support. They did this by doing things together as a family and as a couple.

**Role transitions in the Modified caregiver phase.** In this phase, the spouses became better at developing coping skills and thus may have found some role transitions somewhat easier to navigate. Role transitions in this phase focused on more self-imposed transitions where the spouses started to take control of the changes they wanted to see in their marital, family and interpersonal relationships. Some examples of the role transitions in the Modified Caregiver phase included: future planner (retirement, finances, vacations), restorer of balance to marital relations, sexual intimacy initiator, relationship fosterer, and ultimate advocate (seeker of independence and meaning for spouse) (see Table 9). This was also a time where the well spouses could transition their focus more to their selves and engage in more self care, participate in more individual social events, and focus on their own health.
Table 9

Some Examples of Role Transitions in the Modified Caregiver Phase

<table>
<thead>
<tr>
<th>Role Transitions</th>
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</thead>
<tbody>
<tr>
<td>1. Ultimate Advocate</td>
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<tr>
<td>2. Medical information specialist</td>
</tr>
<tr>
<td>3. Chronic healthcare system navigation specialist</td>
</tr>
<tr>
<td>4. Information gatherer; service seeker</td>
</tr>
<tr>
<td>5. Becoming a worker or giving up being a worker</td>
</tr>
<tr>
<td>6. Single parent</td>
</tr>
<tr>
<td>7. Increased Self Focus</td>
</tr>
<tr>
<td>8. Emotional Pillar of Household</td>
</tr>
<tr>
<td>9. Ultimate decision maker</td>
</tr>
<tr>
<td>10. Household manager</td>
</tr>
<tr>
<td>11. Social convener, relationship navigator</td>
</tr>
<tr>
<td>12. Future Planner</td>
</tr>
<tr>
<td>13. Restorer of Marital Balance</td>
</tr>
</tbody>
</table>

Each phase of the caregiving trajectory involves small stories regarding situational stressors, feelings, supports, and role transitions and coping responses are a common thread. The theoretical framework (see Figure 2) that was utilized to investigate the data was found to be somewhat representative of the process of the changes that the spouses experienced. A more representative framework however would include coping responses of a reciprocal nature and a process of engagement that occurs within the transaction of stressful events and role transitions as opposed to an end product or outcome of stressful events or transitions.

Figure 4 provides a reference for how a spouse would experience a stressful event and a subsequent role transition within any particular phase of the caregiving in the trajectory. In the revised framework, it is thus theorized that a spouse would experience an event, perceive it to be challenging and experience stress while assessing their resources, engage with the event through various modes of coping which then determine the course of the role transitions which include changes and critical points.
Figure 4. Revised Framework of Stress Experiences and Role Transitions
CHAPTER TEN

DISCUSSION

The purpose of the present research was to explore and understand the experience of spouses of individuals with ABI, particularly with respect to the process of change that impacts their lives. This process of change was examined within the framework of a combined perspective of role transition theory and transactional stress theory. The relationship of coping and stress and role transitions were also explored. Further contextual information was drawn from role conflict, role ambiguity, role overload, role strain, and role stress theories.

Changes in healthcare technology have resulted in a higher survival rate among people (typically middle aged) who experience catastrophic acquired brain injuries. Thus, it appears that there are advances in the acute healthcare system. However, the information gleaned from this inquiry suggests that the chronic care component of the healthcare system in Canada has not caught up with these medical technological improvements and thus, families are often left to provide care and even rehabilitative treatment for a lifetime after an ABI. This situation results in a population of younger spousal caregivers being identified in communities in addition to the older caregiver counterparts whose spouses have a dementing illness. In addition, these caregivers may not initially identify themselves as part of the ABI treatment population because they are not aware that their partner’s cognitive changes are going to be permanent after the illness/injury. Thus, similar to the findings of Gan et al. (2010), it is important to improve diagnoses and information dissemination to families to ensure more efficient access to services.
Personal Changes after Brain Injury

The findings suggest that there are many things that are different about the brain injured spouses and some of these differences were viewed as positive or negative by their spouses. Ultimately, the well spouses had to adjust to all of these changes. The brain injured spouses were described as “not the same person”. They exhibited changes in memory, other cognitive skills (such as multi-tasking, problem solving, planning and organization, initiation, and decision making), behaviour, mood and personality. These findings are consistent with much of the literature produced in the area of moderate to severe ABI (see Svoboda & Richards, 2009). Other troubling changes included lack of personal insight, lack of self-confidence, and loss of sense of self. All of these changes combined, resulted in increased dependence on the well spouse, and lack of daily productivity; thus, creating a caregiver dynamic.

Interestingly, some positive changes in personality were described. Some of the participants reported that they were pleased that their partner had become more agreeable, and more importantly more sociable. These changes that were viewed as positive, enabled the some of the participants to make positive changes in their lifestyle such as having less domestic arguments and engaging more with neighbours or other social activities as a couple. This information may be helpful for healthcare practitioners working with clients who are trying to help them to identify positive aspects of their situation in order to better cope and adjust to their role transition. The brain injured spouses themselves reportedly lacked insight about the extent of their injuries and losses and this helped them to better adjust to their brain injury compared to the well spouses and this finding was consistent with various published findings (Gan et al., 2006; Holm et al., 2009).
Caregiving Frameworks and Trajectories

The general objective of the study was to focus on the process of caregiving for spouses of individuals with ABI. Of particular interest was the finding that each of the spouses transitioned through a fairly common and comparable process of caregiving. That is, through the narrative analysis of the overall story structure it was determined that the process of progression in the stories regarding caregiving were similar amongst the participants. Ducharme et al. (2009) found that timing interventions at transition points in the course of caregiving for people with dementias was the most effective in helping the caregivers work through role transitions, and this recommendation was based on the knowledge that these caregivers experienced similar transition points in their caregiving process. Identifying transition points and stages in caregiving to determine effective timing of professional intervention has also been well documented by Aneshensel, Pearlin, Mullan, Zarit and Whitlach (1995). Similar to prior theories and findings, the findings in this study produced a three phase trajectory of caregiving to best explain the caregiving transition points and process. The three phases included: the Embryonic Caregiver Phase, the Immersed Caregiver Phase, and the Modified Caregiver Phase.

The situational events in each phase were also examined within a combined framework of role transition and stress transaction theory. Overall, it was found that the experience of stress elicited engagement and subsequent coping which facilitated many of the role transitions. The theoretical framework exemplified how the intertwined nature of stress transactions and role transitions propel caregivers through the caregiving trajectory or caregiving “career”. Thus, this model, albeit revised, proved to be a beneficial lens for viewing the data. Other studies have attempted to view caregiver experiences through various
theoretical frameworks. Ducharme et al. (2009) used Meleis et al.’s (2000) model of role transitions to qualitatively examine the effectiveness of a psycho-educational intervention program at the time of diagnosis for dementia caregivers in order to assist with the transition into caregiving. They found the role transition framework to be helpful in evaluating their intervention program because it accommodated the temporal nature of the trajectory of caregiving. The findings of the present study found Meleis et al.’s (2000) model to also be relevant to spousal caregiving (in ABI) and further expands on this premise by adding an aspect of complexity to the framework by considering the combined process of the stress transactions, thus contributing new information to caregiver research theory in general.

In the present study, the role transitions did appear to involve the five properties of role transitions outlined by Meleis et al. (2000): acknowledgment, engagement, change and difference, time span, and critical points and events that were identified in the Ducharme et al. (2009) study. Throughout the discussion, these terms discussed in the context of their embedded nature in the spouses’ role transitions. Process and outcome indicators were also found to be inherent in the role transition process. Feelings and perceptions about events along with appraisals of resources were also intertwined in the process of role transitions.

Hammond et al. (2011) utilized Gottman’s (1993; 1994) behaviourally based marital adjustment theory to qualitatively examine marital stability in couples impacted by TBI. Nine dimensions were utilized to evaluate marital stability and some dimensions such as chaos, volatility, and struggles addressed stressful events and others such as gender stereotypes applied to the role changes. The findings illuminated a relationship between acceptance and resistance toward role changes where acceptance was more likely to foster the taking on of new roles. This theory is somewhat similar to the outcome of the combined theoretical
framework of the present study because the present study identified the interactive nature of Meleis et al.’s (2000) concept of engagement and the Stress Transaction model’s (Lazarus & Folkman, 1984; 1987) coping response. Thus, the findings from the present study suggest that the process of engagement helps to implement the coping strategies necessary to initiate and engage with the role transition. Not engaging could thus be likened to resistance.

Previous research models of the experience of caregiving and ABI spouses have involved theoretical examinations of stress and coping and their relationships to burden and quality of life (Chwalisz, 1996; Chronister & Chan, 2006). This study attempted to build upon the theoretical models of Chwalisz (1996) and Chronister and Chan (2006) by employing a qualitative design to investigate a process of caregiving that may change over time as opposed to exploring a conceptualization of caregiving that is fixed in time. Thus, in the case of burden, it was observed in the present study that the spouses experienced burden on many occasions however, this was not the final outcome of their experience because they continued caregiving and some spouses even “modified” their caregiving role in order to address continuous burden.

It appears that the three phase model of caregiving that evolved in this study may be more consistent with the staged models of caregiving described in the dementia literature because these models account for a process of evolvement or change. Donorfio and Kellet (2006) confirmed through their review of several dementia caregiving studies that caregiving is a process that happens over time and thus can involve various stages. The terminating nature of those caregiver trajectories or careers however indicates an inverse process to that of the ABI caregiver trajectory. Of interest however was Donorfio and Kellet’s (2006) findings that adult daughters caring for frail mothers without dementias go through a process
of four stages of caregiving transitions. This research on caregiving stages was most similar to the present study because it did not include a terminal stage but focused on a latter process of acceptance that was also described by the spouses in the present study. Perhaps this desire for acceptance and for improving quality of life reflects the ABI spouses’ need to return to as close as possible to times that did not involve cognitive changes and this could explain the similar processes being observed in these two studies. Donorfio and Kellet (2006) describe an initial phase of “realizing” (p. 163) one is a caregiver and this phase is comparable to the Embryonic phase of the present study where the ABI spouse is thrown into the caregiving role abruptly causing a process of appraising and engaging with their new role as caregiver. Their second phase involves “redefining” (p. 163) caregiving roles which focused more on tasks. There are likely similarities of this phase to the Immersed phase where the ABI spouses became completely immersed in caregiving tasks and problem solving. In the third and fourth transition phases of the Donorfio and Kellet (2006) model that adult daughters attempt to “redefine their caregiving relationship” (p. 163) and they then work toward “relationship acceptance” (p. 164). As mentioned above, these concepts were touched upon by the spouses who reached the Modified phase in the present study. The similarities between the theoretical findings of Donorfio and Kellet (2006) and the present study suggest that there are enough similarities in the caregiving experience (regardless of etiology) to further explore and compare the processes of caregiving for various populations.
Implications of the Three Phases of the Caregiving Trajectory

Phase One: Embryonic Caregiver

The period of transitioning into the caregiver role was instigated by initial crisis of the brain injury or illness onset. A thorough analysis of the data allowed for the development of a three stage process as part of a caregiver trajectory, with the first phase of this trajectory embracing the notion of an “Embryonic Caregiver”. Initially, the brain injured spouses were treated in acute care hospitals and some were later transitioned to rehabilitation hospitals before returning home. During this acute healthcare phase, the well spouses were required to learn many new skills such as: navigating the hospital system, understanding the illness/injury, learning how to interact with the care team, understanding treatment modalities and medications, and advocating for their spouse. Overall, the participants described this time as very stressful due to: the severity of the illness of their spouse, the suddenness of the onset of the illness, and the uncertainties that felt all encompassing. These findings were consistent with Wartella, Auerbach and Ward’s (2009) findings regarding family members’ significantly elevated stress levels during the early phase of the illness onset. Due to the nature of the brain injuries, the transition into the Embryonic Caregiver phase felt premature and most often a surprise, and was consistent with Burton’s (1996) theory about untimely role changes causing stress; and findings regarding the unknowns in caregiver roles (Chwalisz, 1992; Donorfio & Kellet, 2006). The Embryonic Caregiver phase was wrought with uncertainty and ambiguity where the individual was learning how to be a caregiver, which is consistent with literature in the area of role transitions where Meleis et al. (2000) described role transitions as an ambiguous period of change. Overall, the spouses did not expect to be propelled into a caregiving role for their spouses at such a young age.
Factors contributing to role ambiguity, role strain, and role overload. The lack of information contributed to the ambiguity in the spouses’ new roles because they had to learn how to navigate resources on their own. Thus, they developed their own strategies in order to remain engaged in the caregiver role and to successfully complete the caregiver role tasks. Advocating was one of the first skills developed by the well spouses. All participants, regardless of prior experience as advocates experienced role ambiguity because there were uncertainties regarding how to be effective. They were torn between being there for their spouse and taking time to advocate. They struggled with fears of losing services due to “over advocating” or being too demanding of care professionals. Asking about medication changes while advocating was a task that was considerably wrought with uncertainty due to the learning curve required in this area. As discussed earlier, any uncertainty can contribute to role ambiguity for these spouses, thus potentially compromising their transition into the caregiver role or role task mastery/completion. The combination of role ambiguity (uncertainty about what to do about their situation) and role conflict (too many competing roles due to lack of services) resulted in role strain and role overload for some spouses. Feelings of role strain stemmed from uncertainties combined with competing tasks and feelings of role overload were essentially described as feeling overwhelmed. The most debilitating causes of role strain seemed to be related to adjusting to new day to day activities and interactions in the embryonic caregiver phase. The spouses indicated that more help from professionals would have helped to alleviate role strain, role overload or essentially feelings of caregiver burden. The data suggests that this help could come in the form of increased outpatient and in-home services, easier access to information about services, respite services, and funded out-patient or in-home services for ABI patients and their families.
The role of stress and coping within the process of a role transition. Initial stressors for the well spouses included not feeling prepared for the injury onset and this was consistent with the findings of Chwalisz (1992) and Donorfio and Kellet (2006) regarding stress and untimely role transitions. Having been a caregiver or having worked in a helping position in the past reduced stress for those types of individuals. This was similar to Chwalisz’s (1996) findings that spouses with previous caregiving experiences experienced less stress and Meleis et al.’s (2000) findings regarding higher levels of perceived self-efficacy leading to more successful role transitions. Thus these spouses may have felt more prepared for their caregiving role and were subsequently better able to cope.

Thus, in accordance with Lazarus and Folkman’s (1984) Transactional model of stress, the spouses experienced stress when the demands of their situations were greater than their perceived resources. Hammond et al. (2011) found that husbands eased into the role of caregiver more easily than women and the lack of ease into caregiving roles lead to feelings of separateness and dissatisfaction in the marriage for the caregiver. In the Embryonic phase of the present study, the lack of knowledge about brain injuries and lack of information about resources, acute care, chronic care, and community supports served to cause many of the spouses to perceive that they lacked resources and/or the skills to deal with their new role. When the spouses perceived that they did not have the adequate resources, they then engaged in various processes of coping. They eventually developed skills such as advocating, knowledge gathering, and healthcare management. This finding incorporates Meleis et al.’s (2000) role transition theory that suggests the elements of a successful role transition include the development of new skills and knowledge. The skill of advocating was found to be wrought with a significant amount of uncertainty and was a role that was quite ambiguous for
the spouses. Overall, uncertainty and role ambiguity were found to be quite embedded in the Embryonic Caregiver phase. Implications from these findings suggest that acute care workers involved in the initial healthcare phase for these families could focus on teaching advocacy skills and navigating particular areas to advocate.

Access to healthcare in the acute phase of illness/injury was found most often to be easier than access to healthcare in the chronic phase. When people with brain injuries are released from acute care to home or from the rehabilitation hospital to home, the family is left in a situation of requiring continued healthcare services. This involves having healthcare professionals come to their home or attending numerous appointments at various hospitals, rehabilitation centers, and specialists’ offices. Overall, the participants noted that this was a time of continued uncertainty and stress as they did not know what services they needed or where to find the services they felt they wanted. Spouses were left in an ambiguous role of having to develop their own strategies and methods for helping their brain injured spouses and subsequently experiencing increased stress and strain due to this ambiguity. This was consistent with previous studies that have identified that chronic care for these individuals should be a priority to be addressed within the healthcare system (Boschen et al., 2007; Gan et al. 2010). The participants were forced to engage in various coping strategies to address these issues. The findings regarding the initial role transitions that the spouses encountered in the Embryonic Caregiver Phase are consistent with the organizational and industrial psychology literature regarding role ambiguity and role conflict leading to role strain (Coverman, 1989; Jex et al., 2003). Thus, it is likely that role ambiguity and role conflict occurring in the caregiving dynamic can result in caregiver burden.
A critical point in the process of role transitions leads to a new phase. Meleis et al. 2000 theorized that numerous critical points can occur during the process of role transitions and these critical points may change the trajectory of that transition. Many people focus on past, present and future events when organizing their lives. The findings of this study describe a phenomenon after brain injury where the family is forced to slow life down and focus on needs in the moment and this phenomenon was identified as a critical point. The well spouses described their brain injured partners as being limited in their abilities to plan for the future and uninterested in dwelling on the past, leaving them to be almost completely focused in the present. The well spouses found it was easiest to also become focused on the present in order to effectively care for their spouse. When the well spouses came to the realization that they were mostly focusing on the moment (present), there was a shift in the trajectory of their role transition(s) and they ultimately moved into the second phase, the totally Immersed Phase of Caregiving where all of their daily efforts were focused on the brain injured spouse and minute to minute functioning of the household.

Phase Two: Immersed Caregiver

The Immersed Caregiving Phase emerges when the well spouse and family unit modify all or most activities toward facilitating the recovery of the brain injured individual. As identified earlier, this process appears to be similar to Donorffio and Kellet’s (2006) phase of defining the caregiver roles and tasks. Thus, in this phase the focus turns to within the family home. The marker identified in the results of the present study for moving into this phase occurred after the brain injured spouse returned home and the well spouses became more aware of the role transitions involved with living in the moment. The findings indicated that overall the spouses experienced role overload in this phase because more role transitions
emerged and the well spouses engagement with social supports continued to decline. During this phase, the spouses began to disconnect further from their supports because they wanted to manage more independently and did not want to continually ask for help from others and/or their relationships with others were deteriorating. This phase introduced a host of new stressors such as finding appropriate care/treatment, disintegration of relationships, navigating work, parenting demands, managing households alone, and managing decisions alone; these stressors and new roles combined contributed to caregiver burden. Thus, the well spouses continued to experience stress in this phase because the demands of their situations often appeared to outweigh their resources in accordance with the Stress Transaction Model (Lazarus & Folkman, 1984; 1987).

**Factors contributing to role ambiguity, role strain, and role overload.**

Interestingly, the data revealed that particular roles or aspects of roles (i.e. advocating, finding information) contributed to experiences of role ambiguity in the embryonic caregiver phase. In the Immersed Caregiver Phase, feelings such as guilt and anger largely appeared to contribute to subsequent experiences of role ambiguity. Experiences of role conflict on the other hand were more consistent across the two phases where this experience seemed to stem from feelings such as frustration.

The initial months after coming home was an unsettling experience for the well spouses as they had to start learning about all that was different for their spouse both physically and cognitively. The findings revealed that the well spouses automatically began to take over all of the roles within the household contributing to role overload and subsequently leading to feelings of stress and caregiver burden. These findings were consistent with Gan et al. (2006) who also discussed the fact that the well spouses took on
many new roles within the household. As might be expected, these role changes were
difficult for the spouses to accept. Hammond et al. (2011) identified the importance of the
importance of accepting of roles and impacts on marital adjustment and stability in spousal
caregivers. During the first year or two post injury, the well spouses found that they could
not leave their brain injured spouses home alone. Unfortunately, they discovered that there
were not many forms of assistance available in the healthcare system to adequately assist
spouses of persons with ABI with this predicament. Hence, this issue further contributed to
role overload as the spouses had to coordinate help or stay home with their spouse if care was
not determined to be feasible.

Additionally, there were opportunities for role reversals in the marital dyad. In any
relationship there may be roles that one partner does exclusively, and these roles become
expected and automatic parts of the relationship. Role reversal has often been discussed in
the Alzheimer caregiver literature regarding adult children and their parents, and refers to the
adult child taking on the parent role for their parent as they slowly experience losses in
memory and cognition (Brody, 1990). In the case of dementia, the parent and adult child are
swapping roles. The findings of this study suggest that there were various roles that reversed
between the spouses such as driving, certain aspects of decision making, and household
management tasks. Some participants discussed how they felt they were taking away roles
such as “head of the household” from their spouse when they were forced to take on a more
authoritative role such as decision maker. Even more mundane roles such as taking over the
driving, instilled a sense of loss in the well spouses. Hammond et al. (2011) also addressed
the impact of gender stereotypes and role dynamics in marriages in spousal caregivers and
found that husbands were less resistant to engage in non-stereotypical roles. The wives’
reaction to the change in roles was reported as based on feelings of resentment, whereas in
the present study, both the male and female spouses linked feelings of loss to difficulties in
the changes in roles within the household with respect to household governance and
management. Role reversal in the context of the marital dyad in ABI has not been
significantly addressed in the previous literature in this area.

Changes in relationships and role strain. The participants went through a process of
changes in relationships in the Immersed Caregiver Phase. The spouses acknowledged that
they and their brain injured spouse related to people differently and that many people in their
lives related to them differently. Many relationships dwindled for the brain injured
individuals, and, many relationships that the couple had together changed or disappeared.
Some of the changes in relationships were very unexpected and thus caused significant strain
for the well spouses and this was consistent with the findings of Anderson et al. (2009), who
found that spouses experienced more psychological distress from the indirect effects of
changes in the family unit (i.e. loss of parent unit) and decreasing social supports.
Essentially, the findings suggest that through the process of taking on and engaging in the
caregiver role, they were often misjudged by friends and family, resulting in a loss of
relationships. Stebbins and Pakenham (2001) found that spouses of persons with TBI were
interpersonally sensitive and had a high need demand for approval from others regarding
their caregiving efforts. They suggest that these factors contributed to their difficulties in
their relationships. They also suggested that cognitive therapy techniques such as cognitive
restructuring to address irrational beliefs may be helpful in assisting these spouses to work
through these issues. Furthermore, the spouses revealed that they became responsible for
managing all of their old and new interpersonal relationships as a couple. This was a new
role transition for many of the spouses who previously relied on their spouse to share this role or oversee this role in the past. Taking on the management of more interpersonal relationships created more opportunities for interpersonal conflict and thus potentially increased role strain for the well spouses. An additional stressor noted during this time, was the tapering off of support initially provided by family and friends because these significant others went back to their normal lives. Many spouses also reduced their engagement with social supports because they did not want to continuously ask for help. Gan et al. (2010) also identified various informal and formal support needs for families of ABI and the informal supports included respite and emotional support from family and friends.

**Role overload and working.** Some spouses continued working for financial reasons and some maintained their work as a method of coping and self-preservation, while others quit their job or took a leave of absence in order to manage in their new Immersed Caregiver role. Whether the spouses worked or not, they maintained their Immersed caregiver status. However, having a brain injured spouse impacted the spouses’ ability to fulfill work roles as there were many interruptions and schedule changes during their work day. These spouses worried about their partner being home alone for safety and social reasons, they also worried about whether or not they were engaging in productive activities. Spouses who stayed home with their spouse were able to put more effort into personally seeing that their partners were engaging in productive activities however they felt more disconnected and isolated from the rest of society. The findings revealed that the participants were confident in their decision to work or not. Many studies have highlighted the need for formal services to address each ABI family’s needs on an individualized basis (Gan et al. 2006; 2010). Thus, supports in the community should accommodate both working spouses and those who decide to stay home.
The role of stress and coping within the process of a role transition. Consistent with the Stress Transaction Model (Lazarus & Folkman, 1984; 1987), the Immersed Caregiver Phase includes the experience of role ambiguity combined with role conflict appeared to lead to role overload, an overall feeling of being overwhelmed, or, what is described in caregiver literature as “burden”. Above, the participants describe the ambiguity of not knowing exactly how to carry out a role (i.e. managing household) along with having many competing roles leads to feelings of burden and being overwhelmed. The data suggests that for this population of caregivers, this experience of role strain, role overload and subsequent burden propels these individuals to seek out ways to reduce their burden. At this point in the caregiving continuum, many of the well spouses appear to decide to try to alleviate role strain through promoting independence in the brain injured spouse. It is apparent that the reasoning is twofold, first, the well spouses realizes it is best for their partner to gain some independence in order to achieve a higher quality of life and the second would be to reduce burden resulting from the number of new roles.

Feelings of guilt are associated with role ambiguity and role conflict and this impacts role transitions. Due to the lack of services and in the chronic phase of health care and/or lack of financial resources, many of the spouses had to take on the various roles potentially including: physiotherapist, occupational therapist, nutritionist, nurse, healthcare worker, personal support worker, personal life coach and counsellor. Taking on these roles was unexpected as the spouses had preconceived ideas about the support available within the healthcare system along with the unexpected nature of their caregiving role for their spouse. Here the demands between the role of wife/husband, caregiver, and many more were incompatible leaving the well spouses to feel very conflicted. Furthermore, the findings
suggest that taking on an “authoritative” role with a spouse such as “physiotherapist” or “nurse” lead to conflict between the well and unwell spouse as the brain injured spouse would reject the well spouses attempts at fulfilling that role (i.e. refusing to take medication, refusing to physiotherapy exercises). Thus it seems that this type of role transition created immense conflict for both the well spouse and the brain injured spouse. This type of issue has not been previously addressed in the literature and is important to highlight as this type of flaw in the healthcare system (lack of services) can create significant strain for a family dealing with brain injury. Thus, it is recommended that significant efforts be made to address longer term healthcare considerations in the areas of home based healthcare services for persons with brain injuries.

Feelings of loss related to role conflict and subsequent coping. The brain injured spouse can no longer effectively parent and make decisions and thus the well spouse experiences a loss of having a partner in these roles in the household. Overall, these couples experience loss of the family unit as it once was conceived and must transition and adjust to create a new type of family unit. These findings reflect those of Anderson et al. (2009) regarding the impact of changes in the family unit on the well spouse. Many of the participants discussed having interpersonal problems with family supporters and close friends where they felt they were let down and not supported after leaving the hospital and acute care supports. Some spouses were not able to identify the reasons why the expected support was not offered. The outside family member’s failures in offering support lead to feelings of isolation, frustration, disappointment, and sadness for these participants as their expectations in these relationships were not being met. Furthermore, the conflict that this created in the familial relationships created the potential for developing a new role, which was, taking on
the responsibility of addressing these issues and possibly being responsible for creating further interpersonal conflict. Losses in social relationships/supports culminate in this phase and the participants noted that many relationships became permanently severed.

The feelings of loss also contributed to the experience of role conflict and stress as the demands of taking on the decision maker role or other roles requiring significant responsibility and the demands of these roles were incompatible with the desires of the well spouse. The well spouses felt so conflicted about these role transitions that they attempted to include their spouse in decisions and other conflicting roles in order to moderate or cope with the loss. It emerged that the well spouses’ awareness of the imbalance created in the relationship by these conflicted role transitions propelled them to focus on ways to rectify the balance in the relationship. According to Meleis et al. (2000), this awareness is a good indication that the spouse is effectively negotiating or coping with a role transition. Hence, it was subsequently found that these spouses engaged in efforts to establish effective coping strategies. Clinicians working with spouses in a support group or individual therapy could strategize with their clients about appropriate ways to restore balance in the relationship.

A critical point in the role transition process leads to a new phase. As discussed earlier in Embryonic section of the discussion, a critical point appeared to change the trajectory of the caregiving process in the Immersed Caregiver Phase. The spouses engaged in a process of pursuing more independent and meaningful activities for the brain injured spouses in an attempt to restore balance and return to some of the old roles in the marital dyad. This critical point appeared to propel the spouses into the beginnings of the Modified Caregiver phase.
Phase Three: Modified Caregiver

During The modified Caregiver Phase the spouses appeared to have more control over stressors and their ability to cope with stressors. The phase involved more positive dialogue and feelings about their situations. The spouses actively tried to restore balance in the marital dyad and they tried to assist their spouses in returning to some of their old roles. Moving forward and finding happiness in their new life scenarios became the focal point of their daily endeavours. Of note this type of phase has not been identified or described as separate from a “chronic care phase” in previous ABI literature.

There were less factors contributing to role ambiguity, role strain, and role overload. In this phase, less stressors overall were noted by the spouses. One significant stressor noted was feeling reluctant to engage in sexual intimacy because their partner is a different person and much more vulnerable. This created an imbalanced power dynamic and subsequently an ambiguous role for the well spouse because they are not sure how the brain injured spouse perceives their own role in sexual intimacy. The brain injured spouse’s loss of self results in a loss experienced by the well spouse as they feel they cannot emotionally connect with their partner in the same way. Furthermore, the power imbalance that was created by the new dynamic resulted in an ambiguous role for the well spouse because they were not sure how the brain injured spouse perceived their own role in sexual intimacy. Ultimately, the well spouses were left feeling lonely due to this change in ability to connect with their spouse in a way that they were accustomed to connecting before the injury. This issue appeared to be present throughout the caregiving trajectory however it became more salient in this phase because the well spouses were more focused on doing things together and restoring old roles.
Finding meaningful and independent activities for the spouses became stressors in this phase. Ultimately, many of spouses discussed their motivation to address this *critical point* because of its importance to the quality of life for the brain injured spouses. The trial and error nature of finding appropriate activities caused the well spouses to experience role ambiguity and role strain due to the many failures they experienced. Lack of resources in this area contributed to their concerns. Thus, fostering independence and engagement in meaningful activity for the brain injured spouse served to reduce stress for the well spouses. Catalano, Pereira, Wu, Ho and Chan (2006) have identified that engaging in meaningful and productive activity improves quality of life for individuals with ABI. From their findings, they recommend assisted job placement and supported employment through social services can be beneficial for successful employment outcomes.

**The role of stress and coping within the process of role transitions.** Even though there were less stressors in this phase, the well spouses were *aware* that they still experienced stress and psychological distress. They also appeared to realize that *re-engaging* with supports was an effective coping strategy that reduced their experience of caregiver burden. Ergh, Rapport, Coleman, and Hanks (2002) found that social support was imperative for moderating psychological distress and the more supports available translated into less distress experienced by the spouses. Thus, for the current study, the spouses who *re-engaged* with supports were able to transition into more productive relationships and they were able to more successfully navigate their role transitions related to caregiving.

*Striving for feelings of positivity and achieving acceptance were the most successful coping skills to master.* One of the most defining aspects of the Modified Caregiver Phase in the caregiver trajectory is the well spouses’ determination to strive for acceptance. Perhaps
this is a trait that separates these spouses from those spouses of brain injured individuals who do not remain in the marriages. The spouses suggested that this type of acceptance was achieved by focusing on the positives, finding old and new activities to do together, and making plans for the future. Donorfio and Kellet (2006) also noted this phenomenon in caregivers for frail parents. The factors that motivated the spouses throughout the caregiving process in the present study were found to be love, loyalty and commitment. Other motivators include inner strength, faith, and fear of failure. Hence, the findings suggested that these spouses engaged in a process of immersing themselves in acceptance, and this process can be likened to the process of coping described by Lazarus (1993). Furthermore, this process helped them evolve their constantly transitioning caregiver role.

Acceptance seemed to be the pinnacle cognitive realization or achievement that helped the participants move forward with their lives and in remaining together with the brain injured spouse. Blais and Boisvert (2009) suggested that appraisal-focused coping methods such as optimistic thinking, or having an “effective attitude” were correlated to improved psychological adjustment in spouses. The findings of this study were thus comparable to Blais and Boisvert’s (2009) findings. Although some spouses’ idea of acceptance was initially based on a negative reality (i.e. this is what it is I just have to accept it) and for others a more positive reality (i.e. I can see some of the positive changes so I will accept it and move forward; or I accept out of love and commitment), the theme emerged that engaging in acceptance thinking (positive re-appraisal) propelled the participants forward. This information can be very helpful for treating clinicians as it identifies therapeutic content to engage with in session.
Other Life Altering Impacts that Occur During the Caregiving Trajectory

It was noted that there were aspects of the spouses’ lives that were consistent problems across the caregiving trajectory. These aspects were ultimately stressors and were however focused on more significantly at various points depending on individual experiences. These life altering impacts replicate the findings discussed in a variety of ABI studies (Anderson et al., 2002, Arenhall et al., 2010; Florian & Katz, 1991; Gan et al. 2006).

Mental and physical health. Other factors that continue to impact the caregivers throughout the caregiving trajectory are depression (mental health issues), physical health issues, financial issues, and impacts on children. In the modified caregiver phase, some spouses continued to struggle with their own mental health and continued to seek out treatment for depression. These issues have been identified in many studies (Blonder et al., 2007; Gan et al., 2006; and Larson et al., 2005) however, in this study some insight is provided regarding how these issues evolve over the caregiving trajectory. Many of the spouses experienced their own health problems after the brain injury of their spouse. Many struggled with fluctuating weight and eventual weight gain and subsequent issues with hypertension. The data does not suggest there is a direct link between the health concerns of the participants and their caregiving status; however, any additional health concerns compounded stressors for these spouses as they had to make arrangements for themselves for treatment and care for their brain injured spouses.

Sexual intimacy. The findings revealed that the spouses found discussing problems with sexual intimacy to be difficult to share and they were not discussing these issues with their closest supports. The spouses indicated that they felt uncomfortable sharing any information regarding sexual problems and hence as a whole, they were very interested to
know if other spouses were experiencing similar issues. Losses in the sexual relationship included changes in sexual contact, changes in the initiation of sexual contact, limited or no sexual contact, limited or no discussions about sex, reduced sexual drive or acknowledgement of sexual drive in the brain injured spouse, and failure of the brain injured spouse to recognize any changes or problems in sexual intimacy. Changes in the quality of sexual relationships in these couples were also identified by Arenhall et al. (2010).

Finances. It came forward from the findings that the spouses had different financial implications resulting from the loss of income of one spouse in a partnership suffering from a brain injury. Obviously, there were greater implications for losing the income of the “major bread winner”; however many families were able to adjust their lifestyle to accommodate the loss of income. Many made sacrifices such as taking on extra jobs and changes such as spending less in order to address their finances. Many of the female spouses had difficulty adjusting to managing financial investments, and large scale expense decisions. Overall, the spouses were most disappointed by the lack of coverage for extended health care services such as physiotherapy where funding did not continue into the chronic phase of recovery leaving many families to resort to buying their own equipment and attempting to do the exercises on their own. Some families were content with their finances and did not report concerns about future finances. The extent to which families in Canada are financially impacted by brain injury has also been addressed by other studies and practitioners (Buschenfeld et al., 2009; Gan et al., 2010; Hutchinson, 2010).

Impact on children. The findings revealed that the well spouses they relied on their child’s ability to adjust to their other parent’s brain injury in the context of the family and social supports around them. The spouses reported that their children experienced feelings of
loss, grief, and stress and that they often had to take on more responsibility in the household. Some children entered in a role reversal with their ill parent, having to help and take care of the parent at an early age. It is likely that this type of role reversal at such a young age could substantially impact the psychological development of these children. Likely these role reversal experiences are different than that of adult children caring for parents with dementing illnesses, and this topic warrants further exploration. Unfortunately, the relationships between the brain injured parents and the children changed where some children became easily frustrated with their parent causing many arguments. Consequently, as discussed in previous studies, these children are likely in need of some kind of emotional support services (Florian & Katz, 1991; Gan et al., 2006). Overall, it was very difficult for the caregiving spouse to find support for their children when they were completely immersed in the care process for their brain injured spouse. The consensus that prevailed was that more services for children are required in Ontario and that it would be most helpful if healthcare professionals assisted with enrolling children in any support services. Of note, some of the positive changes in the children included increased responsible behaviour, a greater inclination to take on helping roles in society, and having more compassion for disabled individuals. Helping these children understand the important strengths they have developed in the process of their parent’s injury may help to improve damaged self-esteem and mood problems.

**Support needs identified.** Many of the spouses reported that they had participated in a support group because they needed to connect with others and seek outside sources of emotional support. Cuijpers, Hossman and Munnichs (1996) suggested that support groups should improve well being while reducing burden and preventing mental health problems.
The spouses identified that feeling connected with others through a support group or other resources was very important because they had become disconnected from others in their social and family lives due to the onset of their spouse’s brain injury. Golden and Lund (2009), found that making the connection that others were experiencing the same thing with their spouse was very important for the spouses because they felt alone and isolated, and learning this information helped to reduce those feelings. It was identified that potential benefits from participating in some form of social or emotional support may include reducing isolation and the coinciding thoughts that no one else is experiencing what they are experiencing. Meleis et al. (2000) have identified this as an important process indicator for role transitions because making comparisons was found to be important for situating oneself in a role transition. The spouses also indicated that at various points in the caregiver trajectory they needed information about services and practical matters such as filing taxes, disability pensions, disability subsidies, wills, access to disability services, long term disability plans and pension planning. Furthermore, these individuals were interested in getting as much information as possible regarding brain injury itself. Thus, it is likely that some form of formalized support and intervention would be beneficial for this group of spouses.

**Coping Processes in the Caregiver Trajectory**

Coping was described as a process of trial and error where the individuals tried various methods of coping and experienced successes and failures. This finding was similar to the process of coping described by Lazarus (1993). Both problem focused and emotion focused coping strategies were utilized by these spouses. The spouses developed many new coping skills by learning in the moment and by learning from others in a support group.
**Problem based coping.** Essentially all of the participants in this study were engaged in problem based coping as they all had actively sought out memory rehabilitation for their brain injured spouses. Attending neuropsychological memory rehabilitation provided the spouses with a sense of hope that their partner would become more independent subsequently reducing their stress. These findings match those of Chwalisz (1996) who theorized that spouses perceived their situations as less stressful when they employed problem focused coping techniques. The findings also revealed that males were more likely to discuss their problem based coping strategies compared to females. Some of the notable problem based coping strategies included developing skills such as: dropping difficult discussions until the brain injured spouse forgets, backing off from heated arguments, improving listening skills, and creating cognitive compensatory strategies such as the use of a backpack. The spouses reported that these problem focused strategies were effective for reducing stress in the environment and in the moment and this was consistent with Lazarus (1993) who identified this purpose for problem focused strategies.

**Emotional based coping.** The types of emotional based coping strategies that were identified in the study were: exercising self control, utilizing emotional supports, engaging in self care, avoidance behaviours, and cognitive appraisal strategies. It emerged that the spouses exercised self-control of their emotional reactions to friends and family in order to cope. This was consistent with the “effective attitude” identified by Blais and Boisvert (2009) and this attitude was found to be useful for fostering adjustment. Seeking out social support was an emotionally based coping strategy that was found to be used by all of the spouses (particularly in the Embryonic phase and then the Modified phase), and acquiring social support is frequently cited in the ABI literature as one of the most beneficial coping
strategies (Boschen et al. 2007; Chronister & Chan, 2006; Ergh et al., 2002; Gan et al., 2006). Social support was sought out to increase personal happiness and life satisfaction, and it served to enhance the individual’s internal locus of control. Sources of emotional support included friends, family members, colleagues, counselling professionals, and support groups. Of note, the well spouses did not often seek out emotional support from their brain injured spouse as they did not want to worry or distress them and this was a significant relationship change for most partners.

Many of the participants attempted to engage in self care and they revealed that in the initial phase of caregiving this was a very difficult goal to achieve. Successful attempts at self care were achieved after a significant amount of time elapsed after the injury; many spouses revealed that it took up to two years before they could successfully engage in activities for themselves. Enjoyable activities included: going for walks, reading, going to a spa, going out with friends, playing sports, and attending social events/gatherings. Going to work was also identified as an appropriate emotional based strategy for coping. Some spouses returned to work out of financial necessity but many returned out of emotional necessity. It was determined that many individuals found work to be an excellent distraction; many enjoyed the social nature of work and keeping their mind focused on things outside of the home. Those spouses that returned to work reported that they were happy with their decision and that they felt it was beneficial for their own mental health as well as promoting independence in their brain injured spouses.

**Appraisal focused coping.** Learning not to sweat the small stuff emerged as an appraisal based coping strategy that was employed by the spouses. The spouses ultimately learned that “larger” things in life were more important such as living, love and family and
that they could choose not to worry about smaller and more trivial issues. Many of the
spouses were able to maintain this outlook throughout the caregiving trajectory. The
appraisal focused coping strategies included adjusting thinking and expectations in
relationships in order to better cope with their spouse’s brain injury. Furthermore, they
changed the way they prioritized tasks at home and at work. It emerged that the spouses
changed their perspective about many important life issues causing a shift in the way they
approached life. After gaining a new understanding of the complexities of relationships, they
learned to let failing interpersonal relationships go and to start new more meaningful
friendships.

Positive reappraisal was an important coping skill, and this was fostered by hopeful
thoughts and feelings. The findings revealed that spouses actually attempted to alter their
thinking to focus more on positive aspects of their life instead of dwelling on negatives in
order to cope. Finding a positive focus involved being happy in the moment and learning to
appreciate things that instilled happiness on a day to day basis. The spouses indicated that
they were able to focus their attention on positive experiences and hopeful thoughts in order
to positively reappraise their lives. Interestingly, the process of positive reappraisal helped
the spouses move toward acceptance of their new lives, and this acceptance was crucial for
coping in the modified caregiver phase as these people strived to establish balance,
connection, and new meaning in their permanently altered connubial relationships. As
discussed by Lazarus (1993), it was evident that the spouses utilized this emotion focused
coping strategy to cope with a situation they could not change (the brain injury itself), and
they found ultimate success with this approach. An interesting component that also
contributed to acceptance was experiencing the feeling or thought that there are others in the
world that are worse off than oneself. The type of thinking that “other’s have it worse” helped propel the spouses into acceptance of their situation and is another example of focusing on the positive. The participants could not always articulate how they arrived at this particular world view, however, it emerged that all of the participants eventually engaged in this manner of thinking at some point in the trajectory of caregiving phases. As suggested in Lazarus’s (1993) theory about the process of coping, many of the spouses in this study were able to attach personal meaning to their stressors and this helped them to significantly reduce their impact. Thus, they achieved mastery of various coping skills.
CHAPTER ELEVEN

CONCLUSIONS

Limitations and Strengths of the Current Investigation

The findings of the present study were intended to reflect the experiences and process of change for spouses of individuals with ABI. The overall findings involved both strengths and limitations; however the strengths include important contributions to literature in the area of spouses and ABI. These factors are described below and provide implications for future research in this area.

Limitations

It is acknowledged that there are some limitations to this study. The study was retrospective in nature and some participants were recounting information from up to 10 or more years in the past. Thus, it should be pointed out that their perceptions of historical events could accidently be slightly skewed based on experiences of the re-telling of stories over time and/or forgetting that are a part of the normal experience of human nature. It should be noted that the findings of this qualitative study are based on a relatively small sample and thus generalizations are limited. Within the issue of generalizability stems the nature of the relationships of the spouses who participated in this study. Of note, all of the participants in the study had remained in their relationships with their brain injured spouse after the injury onset and thus their experiences are only representative of couples who remain together after such a traumatic life event. Any recommendations made are based on stories that emerged from this subset of individuals. Thus, experiences of those couples who do not stay together could be markedly different. Additionally, all of the couples were
heterosexual, thus possibly providing further limitations based on the sexual orientation of couples.

Additionally, issues related to culture (and sexual orientation) were not incorporated into the findings of this study and thus recommendations made should be viewed and implemented through an appropriate cultural lens based on individual client needs. For this reason, professionals utilizing the theoretical recommendations from this study should consider the culture and individual characteristics of the individuals they are working with when introducing any of the discussed strategies and techniques or in other research endeavors.

Furthermore, the phases identified in the caregiver trajectory may be perceived as restrictive by practicing clinicians and it should be noted that the trajectory was not meant to provide a strict reference but a more general guideline to illustrate the flow of the caregiving experience. Currently, these findings are foundational and theoretical and would need to be validated in future studies of this population. Nonetheless, practitioners who may be influenced by this information should thus acknowledge the individual differences in their clients that may not fit with the flow of the caregiving trajectory described in this study. Accommodating these individual differences in treatment may be necessary. Thus, a limitation in providing a staged trajectory is that individual needs or experiences may be overlooked and/or not recognized because a practitioner or layperson is attempting to identify the particular stages described in this study. Staged models of psychological phenomenon have also been criticized for being too simplistic and for the finite nature of the stages (Rutjens, van Harrevel, van der Pligt, Kreemers & Noordewier, 2012). Thus, the limitation of exploring a staged trajectory of caregiving may reduce the observed phenomenon involved.
into terms/descriptions that are too simplistic and thus have the potential to minimize the complexities of the phenomenon. This issue could be explored in future research with regard to the staged findings of this study. The first stage in the caregiving model (Embryonic phase) in this study is also described as finite which could be considered to be too restrictive in the interpretation of the data. The second and third stages (Immersed, Modified) however were determined to be reciprocal in nature and thus may not be subject to the same limitations or scrutiny in the realm of discontinuity.

**Strengths**

The present examination of the lives of spouses of persons with ABI has allowed for a glimpse into their daily experiences and resulted in a picture of the overall process of change to their lives. Caring for and maintaining a marital relationship with a spouse who has endured an acquired brain injury can be a very stressful and traumatic experience involving many transitions. Spouses who engage in caring for their spouse and maintaining their family unit ultimately become consumers of the healthcare system alongside of their brain injured spouses. A strength of this study was that it has replicated the findings of other studies, in that this population of individuals requires several types of support from our healthcare system, and that their healthcare needs are most often not being met. The types of supports that these individuals require ranges from chronic medical care services (home services) to their own mental health support. Another strength of the findings was that the study revealed more detailed information about the potential forms assistance that the spouses would like to have received from professionals within the healthcare system and from other sources. Thus, themes emerged regarding the various support needs required by the participants and also important information regarding the potential timing of introducing these supports. They
suggested that help from professionals or accessing other types of supports would have helped them to better cope with their situation at various times throughout the caregiver trajectory. Overall, through each of the three phases of caregiving, the participants reported about the areas where they encountered a lack of support and these areas consistently were: professional healthcare services, availability of information related to brain injury and brain injury services, financial supports, and social/community supports.

Another strength of the study was its new contribution to the literature regarding the process of change for spouses of individuals with ABI. With regard to role transitions, the findings revealed that the spouses experienced the five properties of role transitions described in the theory of Meleis et al. (2000), and these properties included awareness, engagement, change and difference, span of time, and critical points and events. Awareness, engagement, change and difference and critical points were identified overtly in the discussion chapter while span of time was considered to be self-evident as an underlying factor of the transitions in the caregiving trajectory. With regard to the three phases of caregiving described in the findings of this study an overall gestalt for their story emerged, and this was a strength inherent in the findings. In the Embryonic Caregiving Phase the containment of these spouses’ families that they had worked many years to achieve appeared to fall under attack by an inordinate amount of stressors and people (professional, personal) intervening in their lives. Thus, it is not surprising to observe them to react by retreating into their home life and nuclear families as they moved into the Immersed Caregiver Phase in order to achieve control over the rehabilitation of their spouses and their households. Once the external stressors and interactions with medical treatment began to reduce many of the spouses were able to move into a Modified Caregiver Phase where they re-initiated more interaction with
outside social supports and they altered their view of their situation in order to move forward and find acceptance. The findings regarding the trajectory are important because they identify not only what these particular spouses experienced but also insight has been provided into the “how” and “when” certain interventions and supports could be theorized to be helpful. Prior to this study, these questions have been proposed to be explored in many studies in the area of ABI because that had not been adequately addressed in previous publications.

**Future Research**

Boschen et al. (2007) found that the literature in ABI caregiver field lacks scientific examination of interventions for this population of spouses. The findings indicated that there were barriers that prevented the spouses from accessing current healthcare resources, and the reasons behind this finding were unclear. In addition, specific research that investigates the current availability of online resources for various communities would also be helpful because on-line resources are often more easily accessed than other types of information. Future research which investigates the nature of these barriers may be helpful in the elimination of this type of problem.

The study also attempted to explore the needs and issues of these spouses in conjunction with the impact of role transitions and stressors. The findings of this study demonstrate that future research involving the effectiveness of Interpersonal Therapy (IPT) with this caregiver population would be an appropriate and beneficial contribution to the literature regarding effective services for these spouses. Further investigation of the findings regarding the Caregiving Trajectory would be beneficial for enhancing the theoretical framework that was used and the subsequent caregiving model that was identified.
Clinical Implications

This study attempted to explore the experience of spouses of individuals with ABI in the context of role transition theory and a transactional model of stress and coping. Important findings were identified regarding the types of role transitions the spouses experienced and identifying these transitions provides important theoretical markers for healthcare professionals or future researchers to identify. The feelings associated with these role transitions provide a theoretical foundation for exploration in psychotherapy and emotional support. Furthermore, the process of coping and subsequent coping strategies identified in this study has provided theoretical information for identifying strategies in psychotherapy and topics of discussion in support groups. Of note, positivity and acceptance were more strongly linked and present within the modified caregiver phase; thus indicating these appraisal skills should be adequately addressed in treatment when the spouse is ready.

A three phase trajectory of caregiving emerged from the findings which was relevant to the experiences of these spouses. The phases of the trajectory are qualitative in nature and could eventually provide a guide for clinicians working with individuals in comparable situations, once the theory is validated in future research. It is recognized that everyone is an individual and thus there will be differences in experiences, however, there was enough evidence to provide a structure for the trajectory and thus it was explored and described in order to elucidate the findings of the study and to provide a theoretical framework. Within the caregiving trajectory the spouses encountered many stressful situations. The spouses’ perceptions of their abilities and resources to deal with the stressors varied and they eventually engaged in the process of coping. Each phase of the trajectory involved new stressors and stressors appeared to be cumulative through each phase meaning that they did
not necessarily eliminate a stressor when they moved on to a new stage in the trajectory. Most stressors were associated with various role transitions and the subsequent feelings associated with those transitions. Overall, the study established a theory that spouses start in an Embryonic Phase of caregiving and then move to an Immersed Phase and then move to a Modified Phase and potentially back and forth between these latter two phases of caregiving. If this model is further validated in future research, clinicians can thus modify their interventions based on the characteristics of their clients and the phases of the trajectory.
REFERENCES


Retrieved from the Trauma Resource Directory website:


APPENDIX A

PHONE SCRIPT

Hello,

My name is Sandra Belfry and I am a PhD student studying at OISE at the University of Toronto. Dr. (name omitted) provided me with your name so that I could contact you about the research study I am conducting in order to complete the requirements for my PhD. I am looking for participants for my study who are spouses of an individual who has suffered from an acquired brain injury.

Are you interested in hearing about the study?

The purpose of this study will be to understand the experience of spouses of individuals with ABI, and to explore the needs and issues that are relevant to address in a support group. The proposed study is important because there is a lack of exploratory literature in this area. Understanding these experiences and issues would enable healthcare professionals to better target any support or treatment needs. Neuropsychological testing scores for the brain injured individuals will help to provide more information about their cognitive experiences. The proposed research may provide recommendations on how to improve the (name omitted) Support Group and other similar programs worldwide.

If you agree to participate in this study you will take part in an in-person individual interview for one to two hours, which will be digitally audio-recorded. In addition, you will be given an opportunity to review and add information to your interview once it has been transcribed. This process will take 30 minutes. In addition, the investigator may contact you during the data analysis phase by telephone for a 30 minute consultation. I will also ask your spouse if he/she is willing to include their neuropsychological test scores for the study.

Do you have any questions?

If you think you would like to participate you can inform me now. If you would like to think about it I can provide you with my telephone number and you can call me within the next two months.

If yes, a meeting time and location will be decided. Parking reimbursement will be discussed if necessary.

If no, then researcher contact information will be provided.
APPENDIX B

INFORMED CONSENT FORM

An Investigation of Change in the Lives of Spouses of Individuals with ABI

Principal Investigator: (name omitted), Ph.D.

Co-Investigator: Sandra Belfry, M.Ed.

Study Description

The purpose of this study will be to understand the experience of spouses of individuals with ABI, and to explore the needs and issues that are relevant to address in a support group. The proposed study is important because there is a lack of exploratory literature in this area. Understanding these experiences and issues would enable healthcare professionals to better target any support or treatment needs. The proposed research may provide recommendations on how to improve the (name omitted) Support Group and other similar programs worldwide.

If you agree to participate in this study you will take part in an in-person individual interview for one to two hours, which will be digitally audio-recorded. In addition, you will be given an opportunity to review and add information to your interview once it has been transcribed. This process will take 30 minutes. The investigator may contact you during the data analysis phase by telephone for a 30 minute follow-up consultation. The time period for your participation in the study will be a maximum of two months starting from your first contact with the investigator and any subsequent contact for follow up.

You will be informed about any abnormal findings should they arise. If you decide to be interviewed at (name omitted) Hospital, your parking fee of $12.00 will be reimbursed.

Confidentiality

All personal and clinical information is kept strictly confidential. Only individuals directly involved in the research study will have access to your health record. Files are stored in a locked filing cabinet in the (name omitted) Department. Should you consent to your information being used for the purpose of evaluative research, no identifying or personal information will be disclosed in any resulting publication or presentation. If you are interested, we would be happy to provide you with a summary of the final results of the study.
**Benefits and Risks**

Any benefits that you receive from your research involvement will be collective in that evaluative research at (name omitted) contributes to our goal to provide clients and their families with the best available interventions. There are no significant risks anticipated with your participation in this study, but please be aware that you will be sharing personal information that may elicit emotional reactions. If new information related to the benefits or risks of the study is obtained, you will be informed.

**Consent to Research**

Your decision whether or not to participate in this research study is completely voluntary. You may withdraw your consent at any time. Your decision will not affect the care that you, or your family members, receive at (name omitted) or at (name omitted). In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

**Consent to Participate**

I acknowledge that the details of this study have been explained to me, and that my interview will be audio-recorded. I agree to participate in the Investigation of Change in the Lives of Spouses of Individuals with ABI study and to the use of my demographic and/or clinical information for the purpose of this research.

I have read the information above and I understand the purpose of my participation, the procedures involved and the risks and benefits of participating in the study. I understand that my consent to participate in this research is voluntary and that I may withdraw my consent at any point in time with no consequence to the care that I or my family members receive at (name omitted) or (name omitted).

It has been explained to me that the results of the study are confidential. Neither my identity nor any personal information will be available to anyone other than the individuals directly involved in my care or this study. No identifying information will be disclosed in any resulting publication or presentation. I am aware that I will be informed about abnormal findings should they arise. I have been given a copy of this informed consent form which includes information about the study.
Participant Name (please print):

_____________________________________________________

Participant Signature:  

______________________________________________________ Date: ___________

Name of Investigator:  

_____________________________________________________

Investigator Signature:  

__________________ _____________________________________ Date: _________

If you have any further questions regarding this study or other research studies at (name omitted) please feel free to call Sandra Belfry at (omitted), or Dr. (name omitted) at (omitted). If you wish to contact someone not connected with this project about your rights as a research participant, feel free to call Dr. (name omitted), Chair of the Research Ethics Board at (omitted).
APPENDIX C

INTERVIEW QUESTIONS

Questions Regarding Personal Experience
Tell me your story, starting from the time of your spouse’s brain injury.
What is different?
What were your biggest struggles?
How have things changed for you and your family?
What about roles, how have they changed? How do you perceive your role?
What about changes in relationships? Family? Friends?
What about supports?
How do you cope? Any new skills for coping?
What kind of transitions have you had to go through over time?
What markers stand out for you?
What about feeling prepared for these transitions?
Tell me about your perceptions of control over the events in your life.
What about stressors?
What do you miss?
Tell me about how your spouse behaves.
Any problems? What has been the most difficult?
Any changes over time?
What resources have helped with problematic behaviours?
Tell me about their interactions with others.
How would you describe your physical and mental health?
Any changes?
Any worries?
What are the positive factors that contribute to your life now?
What motivates you?

Questions Regarding Support Group Needs
What kind of benefits would you foresee if you were to participate in a support group?
Explain. Or, what kind of benefits did you experience from participating in the support group?
Did you learn any new strategies?
What topics would be helpful to discuss in the support group? Or, what topics were helpful to discuss in the support group?
Feelings?
Strategies?
Information?
Would there be anything about at support group that you expect not to be helpful? Explain.
Or, what kinds of things happened in the support group that was not helpful?
If participated in the support group: Overall, can you describe your experience of the spousal support group?
If participated in the support group: Tell me about the types of interactions between group members in the support group?