An Odyssey: Families' Experiences Living with Acquired Brain Injury

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Abstract

Notoriously known as the ‘silent epidemic’, Acquired Brain Injury (ABI) has reached worldwide epidemic proportions. While ABIs are manifested in individuals, families’ lives are dramatically affected by ABIs. These post ABI changes can directly impact individuals’ and families’ experiences and include a sense of loss. To date, the majority of evidence on how ABI affects families has been provided by examining individual family members who present their views of the “family perspective”. The science on ABI and families is limited in examining the family group perspective of their experiences living with ABI.

The purpose of this research study was to examine families’ experiences living with ABI. This narrative inquiry study, informed by the life-stage approach of Lieblich, Tuval-Mashiach and Zilber, and the narrative analysis model by Riessman, and guided by ambiguous loss theory, used a research approach that included *both* the affected individual family member and the family together as a family group. Transactional data were collected through individual family group face-to face interviews with six different families. Data were also collected through ethnographic methods. Data analysis included an in-depth within case analysis and an across case analysis to identify themes that reflected families’ experiences living with ABI.

Centered on the life stages of before the ABI event, now living with the ABI, and the future, thematic findings included: Families, a grounding force; Losses, individual and family; Family adaptive capacities; Experiences with the health care system-hospital to home; and A patchwork future-entering the unknown.

The thematic findings from this study affirmed the significant impacts of ABI on individual and family members and acknowledged ABI as an ambiguous loss event. However, the findings also illuminated families’ strengths and resiliencies in coping with living with ABI. The study findings suggest minimal supports exist for families impacted by ABI and health care professionals need to acknowledge and attend to the entire family system and not just the individual and primary care giver. The study results suggest by THINKING FAMILY health care professionals can contribute towards a health care model that focuses on ‘family’ as the central unit of care.

Key words: acquired brain injury, family research, families, experiences, ambiguous loss, health care

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Chapter One: Introduction

Notoriously known as the 'silent epidemic', Acquired Brain Injury (ABI) has reached worldwide epidemic proportions. Globally ABI is estimated to affect over 10 million people annually and is acknowledged as a leading cause of death and disability, resulting in immense psycho-social and financial burdens to individuals, families and societies (Brain Injury Society of Toronto, 2014.; Chan, Zagorski, Parsons, & Colantonio, 2013; Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007; Webster, Daisley, & King, 1999). Loss, a universal and psychosocial human condition, is most often associated with adverse life events signifying the loss of something believed to have been meaningful or of value (Murray, 2001; Nochi, 2000). Individuals with an ABI can experience a range of cognitive, behavioural and emotional impairments, often not visible, that may cause significant disruptions and changes to their psycho-social presence and identity. These post ABI neurobehavioural changes impact on individuals' and families' loss experiences.

This study investigated families' perspectives and loss experiences of living with ABI. Research to determine the impact of ABI and loss on the individual survivor is uncomplicated as the evidence about the subjective experience is collected directly from those affected. The research on the impact of ABI and loss on families is unclear. The majority of ABI and family research has relied primarily on the perceptions of individual family members (who have been interviewed or surveyed separately) to present their views of the "family perspective". Although this research furnishes valuable insights on how an individual views family life, this research methodology is centered on the individual's attributes and perceptions of the family and not the greater family dynamics. The family group perspective of their experiences living with ABI is notably under investigated in the science on ABI and families. To address this research limitation and maintain conceptual and methodological congruence, this study employed a family systems framework along with a unit of analysis that included both the affected individual family member and the family together as a family group (Robinson, 1995). This research approach is a critical next step in building knowledge about families' experiences living with ABI that can be useful for informing family centered practice.

The contextual background that framed this study will be presented first in this chapter; followed by: a statement of the problem and the purpose of the study; research questions and approach; assumptions, and the researcher's perspective. Also included is an examination of ambiguous loss theory, the theoretical framework which underpinned this investigation. A discussion of the rationale and significance of this research study and definitions of key terminology conclude this chapter.

Background and Context

ABI is most frequently defined as damage to the brain which occurs after birth and may be caused by: 1) a traumatic event-a result of a motor vehicle collision, fall, assault or sports injury; or 2) a non-traumatic event such as stroke, aneurysm, infection of the brain and or a tumour (Cloute, Mitchell, & Yates, 2008; Fraas & Calvert, 2009; Rosenthal & Ricker, 1999). ABI is not related to: a genetic disorder; a developmental disability (e.g. Down's syndrome); or a process which progressively damages the brain (e.g. Alzheimer's, multiple sclerosis) (Murray, Maslany, & Jeffery, 2006).

Epidemiological data offers further insight as to the breadth of populations affected by ABI. ABI is the number one killer and disabler of people under the age of 45 (Brain Injury Society of Toronto, 2014), and males of all ages are at a higher risk of sustaining an ABI when compared to females (Canadian Institute for Health Information (CIHI), 2006). In Canada, 1.3 million individual Canadians and their families are estimated to be living with ABI (Brain Injury Association of Waterloo, n.d.) with vehicular accidents accounting for over 50% of all ABIs (Brain Injury Society of Toronto, 2014). In the province of Manitoba motor vehicle accidents account for over 200 new cases of ABI yearly (Manitoba Public Insurance Corporation, 2012). For individuals over the age of 65; ABI injuries occur most often as a result of falls and brain tumours (Chan et al, 2013). Amongst combat veterans ABI is the most common reason for discharge (Gubata et al, 2014). Homeless individuals have a higher rate of ABI compared to the general population (Topolovec-Vranic et al., 2012) and for children and young adults ABI is the primary cause of neurological injury (Byard, Fine & Reed, 2011).

The impact and experience of ABI on individuals and families can vary depending on the degree of brain injury acquired (mild, moderate and severe) in combination with which area(s) of the brain were injured. The range of ABI impairments reflecting potential major areas for dysfunction include: physical and sensory impairments (hemiparesis, seizures, loss of taste, smell and touch; fatigue; dizziness and balance; headaches; chronic pain; and visual and hearing problems); behavioural impairments (impulsivity, irritability, lability, inappropriate communication, dependency, withdrawal, and disinhibition); and cognitive impairments (lack of insight, memory problems, concentration problems, planning and problem-solving issues, lack of initiative, inflexibility, depression and personality changes); (Degeneffe, 2001; Pachet, Pinn, & Skowron, 1998). Some brain deficits (as noted above) are not readily ‘seen or visible’, rather they are hidden. Depending on the level of severity of an ABI, the resulting changes in an individual can manifest themselves differently in every person (Alston, Jones, & Curtin, 2012; Chamberlain, 2006; Freeman, Adams, & Ashworth, 2014; Lorenz, 2010).

The ensuing physical, behavioural, and cognitive and personality changes following an ABI event are associated directly with the concept of loss. The impact of ABI on individuals and their corresponding sense of losses have been well documented. As a result of the deficits to physical, cognitive and emotional functioning individuals encounter loss of: employment, education, income, intimate relationships, work relationships, friendships, quality of family relationships, roles as a spouse or provider, leisure activities, and general health (Dijkers, 2004;). The loss of self-identity and its implications have been identified as key issues for individuals affected by ABI (Bryson-Campbell, Shaw, O'Brien, Holmes, & Magalhaes, 2013; Conoley, & Sheridan, 1996; Curry, 2006; Godwin, Chappell, & Kreutzer, 2014; Gracey et al., 2008; Guerriere & McKeever, 1997; Heller, Levin, R., Mukherjee, Reis, 2006; Hoxie, 2014; Inkmann, 2001; Kieffer-Kristensen & Johansen, 2013; Landau & Hissett, 2008; Levack, Kayes, & Fadyl, 2010; Mauss-Clum, & Ryan, 1981; Nochi, 1998a; Nochi, 1998b; Tasker, 2003; Webster et al., 1999; Yeates, Henwood, Gracey, & Evans, 2007). Levack, et al's meta-synthesis (2010), investigating the beliefs, perceptions and experiences of adults with ABI, highlighted the central losses experienced by adult ABI survivors. These pivotal losses included: loss of their pre-injury self, loss of personal control over one's body, loss of their social world, loss of a place in the world, and loss as an emotional process of grief (Levack et al., 2010).

Recognition that brain injury occurs within a family context and families are also impacted and experience losses has been more recently acknowledged by the scientific community (Dell Orto, & Power, 2000; Sander, 2007). Families have been described as the second victim (Rosenthal & Ricker, 1999) and have been reported as identifying: " …the brain injury, once it had occurred, continued to permeate their lives, to the very core, and remained the single most significant characteristic of their existence by which they defined all future life experiences"

(Leith, Phillips, & Sample, 2004, p. 1204). The impact of ABI on families has been described as largely negative and long-term (Brooks, 1991; Dell Orto, & Power, 2000) with: increased levels of burden and responsibility of care for families over time (Degeneffe, 2001; Florian Katz, & Lahav, 1989); continued exposure to prolonged stress and strain and stress related to daily coping (Christensen, Skaggs, & Kleist, 1997); harmful effects on families' social, emotional, structural, and financial functioning; significant role shifts (Brooks, 1991; Kosciulek & Lustig, 1999; Webster et al., 1999); and challenges to core values and resources in families (Lezak, 1988; Mauss-Clum, & Ryan, 1981). Families' fundamental loss experiences center on the realization their loved one is different than before the head injury (Florian,et al.,1989; Williams & Kay, 1991). This perceived loss of a family member who is still alive can have an even greater influence on the psychological health of family members as the presence of the injured member continues to remind the family of what is lost (Webster, et al., Daisley, & King, 1999).

Problem Statement

An ABI event profoundly impacts the individual who sustained the injury. These individual survivors are also part of a family unit. In order to understand the impact of ABI on families it is necessary to obtain family members' perspectives of their experiences. To date, evidence on how ABI affects families has been provided by examining individual family members who present their views of the "family perspective." Although this research furnishes valuable insights about families, the evidence on ABI and families is limited in examining the group family perspective of their experiences living with ABI. A family systems approach purports that individuals cannot be understood in isolation rather they need to be understood within the context of the 'whole' family unit (Smith, & Hamon, 2012; Wright, & Leahey, 2009). Family members interact reciprocally, therefore family members' perspectives are a result of the interplay between each other. For this study, the intent was to access this ‘whole family’ perspective to understand the impacts of living with ABI.

While the evidence exists regarding the significant impact ABI has on individual family members, these members continue to report they require enhanced understanding of their needs and want the family to be considered the primary unit of attention and care (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012; Stejskal, 2012). The family-centered care paradigm, informed by principles of partnership and collaboration, has been garnering attention and evolving within health care over the past 10-15 years (Miller, 2012). However, struggles to fully implement a family-centered practice model remain, as health care practitioners, while considering families to be valuable contributors to treatment, continue to limit family involvement (Levack, Siegert, Dean, & McPherson, 2009).

Families are a complex system comprised of family characteristics, family interactions, family functions, and family life cycle changes (Turnbull & Turnbull, 1991). The dynamics amongst the family as a whole are important to further understand families’ perspectives. I examined families’ experiences living with ABI by applying a unit of analysis that included *both* the affected brain injured family member and the family together as a family group (Robinson, 1995). This empirical approach informed by the theory of ambiguous loss facilitated understanding the family context of ABI and loss; thereby advancing the knowledge of families’ perspectives living with ABI that can be used to inform family-centered practice.

Statement of Purpose and Research Question

The purpose of this study was to investigate families’ perspectives of the impact of an ABI event. Specific objectives included:

1. To understand families’ experiences with ABI.

2. To explore the impact of ABI on families' attitudes, beliefs and identities.
3. To gain greater understanding of families' relational experiences to each other, their community and health care practitioners for the purpose of supporting a family-centered model of care.

The research question was: How do families make sense of their experiences living with ABI? To answer this research question, a qualitative narrative inquiry approach was employed.

Research Approach

This study utilized narrative inquiry to capture family group stories about their experiences living with ABI. An essential quality of human existence is to give meaning to life through the active involvement of interpreting experiences; thus, narrative inquiry allows for meanings to be considered as a basis of people's actions (Smith & Sparkes, 2009).

The borders of narratives move beyond the individual to families as families build narratives (Fiese & Sameroff, 1999). Family systems theory recognizes while people are individuals they are also a part of a family system and that a person's feelings and behaviours are intertwined with and influenced by others in the system (Maitz, 1991). Therefore, as narrative inquiry not only reveals the ways in which human beings interpret their world it can also unveil the ways families interpret their world. Family narratives are built from reflecting on how they make sense of their world, express rules of interaction and create beliefs about relationships (Fiese & Sameroff, 1999). In recounting events, families often co-construct a set of perspectives that personify their struggles (Fiese, & Spagnola, 2005). Meaning making in the family is associated with family adaptations to stressful conditions such as: immigration (Farias & Asaba, 2013); mental illness (Stern, Doolan, Staples, Szmukler, & Eisler, 1999); acquired brain injury (Boss, 2006; Hyden & Antelius 2011; Medved, 2011); infertility (Sandelowski, Holditch-Davis, &

Harris, 1990); and, organic brain issues (Hyden & Orulv, 2009; Hyden, 2011). Narrative inquiry is a useful methodology for examining families affected by an ABI because of its ability to encapsulate how families make sense of their experiences living with ABI through the characteristics of meaning, relatedness, identity, and, time.

The premise of narrative inquiry is to position the researcher to examine the stories people tell about their lived experiences and the meanings or sense making they have developed as a result (Smith & Caddick, 2014). In this manner narrative inquiry is distinct from the reconstruction of stories which is the purpose of narrative therapy. By enabling meaning making conversations to develop between the investigator and family members, narrative inquiry can contribute further knowledge about families' experiences living with ABI.

Theoretical Framework

The theoretical framework which underpinned this study is ambiguous loss theory. Ambiguous loss theory, developed by Pauline Boss, began as clinical observations of "psychological father absence" and advanced through the compilation of decades of research (Boss, 2006). This theory proposes a more systematic view of individuals and their families; therefore, the focus of the theory is on the individual and his/her family as client with specific emphasis on family (Boss, 2006). Other paradigmatic influences include theories from psychology, sociology and family sciences, as well as interventions from family therapy models. Ambiguous loss theory can be categorized as a middle-range theory. First the concept of ambiguous loss will be defined and described, followed by a presentation of the theory's foundational concepts and discussions of application of ambiguous loss theory to research and application of ambiguous loss theory to families' experiences living with an ABI.

Ambiguous Loss Defined and Described

Boss (1999), defined the concept of ambiguous loss as a unique stressor situation in which there is an unclear loss resulting from not knowing whether a loved one is dead, alive, absent or present. There are two types of ambiguous loss: 1) a loved one is physically absent yet kept psychologically present; and, 2) a loved one is physically present but psychologically absent (Boss, 1999). A loved one who has disappeared in body (physically missing) is often kept psychologically present by family and community members, because the loss is not verified by evidence of death (Boss & Carnes, 2012; Boss, 2006). This physical absence could be a result of war, terrorism, ethnic cleansing, genocide, kidnapping, and natural disasters. Conversely, an individual may be missing in mind (physically present yet be psychologically absent) - that is, emotionally or cognitively different (Boss & Carnes, 2012; Boss, 2006). Examples of this type of ambiguous loss include people living with Alzheimer’s disease, dementia, brain injury, AIDS, autism, depression, addiction, or other chronic mental or physical illnesses (Boss, 2006).

Boss (2007) explains that her concept of ambiguous loss is not synonymous with the term “uncertainty”. Boss (2007) asserts that the concept of “uncertainty” as used by the discipline of nursing refers more to diagnosis or prognosis. Boss (2007) also differentiates between the terms, ambiguity and ambivalence. According to Boss (2007) ambiguity originates from an ambiguous social situation that then creates ambivalent feelings and behaviours in individuals. Therefore, the word ‘ambiguous’ within the phrase ambiguous loss refers to an objective situation or event and not the subjective perceptual and emotional responses (Carroll, Olsen, & Buckmiller, 2007). Boss (2007) stated, “Without information to clarify their loss, family members have no choice but to live with the paradox of absence and presence” (p. 105).

Ambiguous situations often are not tolerated well by people. Ambiguous loss is a stressor event and becomes more difficult and stressful the longer the ambiguous loss situation continues without resolution (Boss, 2006). This loss is loss without finality, ‘frozen grief’ (Boss, 2004); so, closure is a myth (Boss, 2016). In either the physically absent or psychologically absent ambiguous state, the result may be unresolved grief as well as an uncertainty about who is in ‘the family’. This uncertainty about who is ‘in the family’ is called boundary ambiguity. It is manifested when families experience role upheavals and disturbances in regular routines and family ritual practices. Boundary ambiguity can also lead to uncertainties in a relationship and to ambivalence about identities for individuals and their families. In cases of psychologically absent ambiguous states difficult questions and thoughts may arise, such as; “Am I married if my spouse no longer knows who I am?”; “I have a spouse, but I do not have a spouse.”; “I no longer recognize my son (daughter) when he (she) is in this mental state”; “This is not the child I once knew;” “Am I only a caregiver?” “Who am I?” These articulations indicate that family members may experience a distortion or reduction in their primary roles such as spouse or parent, diminished emotional connection, and an inability to rely on patterns of interactions that are predictable and consistent. This form of loss becomes a ‘hidden loss’ as it is not readily recognized or legitimized by society. As a result of no definitive forms of social rituals (i.e. verifications of death such as funerals) societal members are not able to validate and support individuals and families experiencing ambiguous loss situations. Therefore, individuals and families can become further isolated, pathologized and burdened.

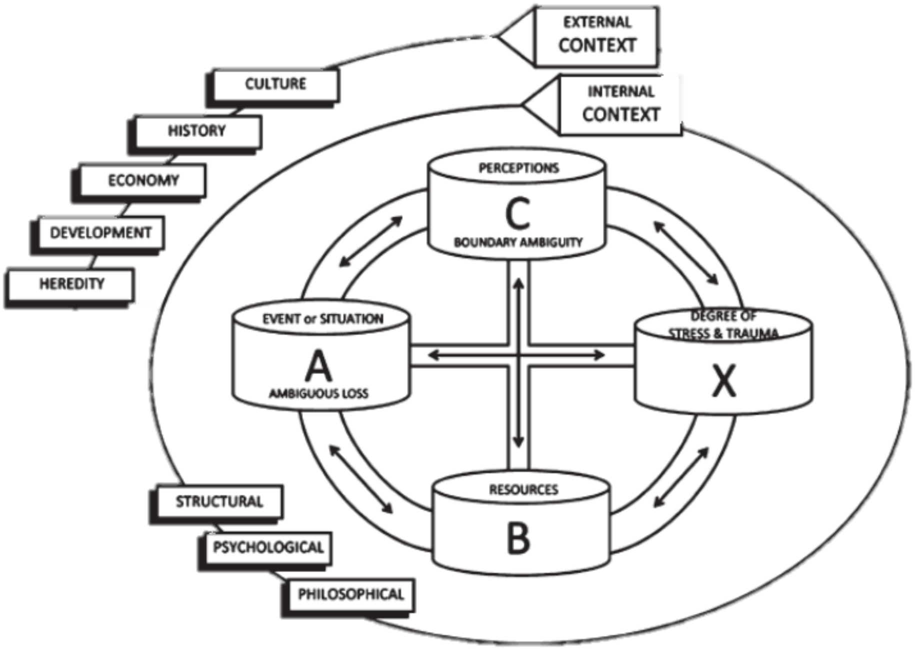
The theoretical positions of ambiguous loss theory can also be utilized to guide therapeutic interventions. In working with clients who are experiencing ambiguous loss therapeutic goals involve: finding meaning, tempering mastery, reconstructing identity, normalizing ambivalence, and revising attachment (Boss, 2006). Seeking meaning involves the ability to make sense of the ambiguous loss. Without meaning, coping and decision making can become more arduous. Being able to accept and tolerate ambiguous loss as an imperfect situation and live well is the goal of tempering mastery. Reconstructing identity is the redefining of roles within the family or community. Acknowledging and recognizing the existence of ambiguous loss is a normalizing process that assists individuals, families, and communities in coping and functioning. Revising attachment involves the process of remaining connected to the individual while simultaneously searching for new relationships. People do not ‘get over’ ambiguous loss rather they learn to live with it by building meaning, and some degree of mastery and resiliency (Boss, 2007).

Foundational Concepts

Psychological family, ambiguous loss, family boundary ambiguity, trauma and stress, and family resilience are the concepts upon which the theory of ambiguous loss was built. The concept of psychological family is defined as an individual’s private ability to create and hold onto psychological (emotional) bonds with people and or places even though the individual maybe absent or cut off from the person (s) or location (Boss, 2006). This is a psychological construction of family and does not have to include the family with whom one may live (Boss, 2006). The concept of psychological family infers that there is no absolute presence or absence required for a psychological connection to be maintained (Boss, 2006). While cognitive processes cannot be witnessed, emotions can be observed and perspectives can be voiced; therefore, this concept appears to have observable qualities. The boundaries of the concept are amorphous as many people can be considered as part of a psychological family. The concept of psychological family is generally understood to occur after the death of a loved one. However, Boss has appropriated this concept and applied it to situations where death is absent, thereby giving it a more nuanced meaning. Western culture has an affinity for finding closure for a loss (Boss, 2006; 2016). Boss (2006; 2016) acknowledges there are other cultures, that through their values are more able to tolerate and accept the psychological connection to missing family members.

The concepts of ambiguous loss and boundary ambiguity are informed by family stress theory, in particular, Hill’s ABC-X family stress model (Boss, 2002). In understanding family stress, Hill proposed three foundational independent variables. ‘A’ is the initiating stressor, ‘B’ is the family’s resources and strengths, and ‘C’ is the individual and family meanings attached to the stressor event. All combine to produce X the crisis (Hill, 1949, 1958). Boss (2002) interpreted Hill’s model by viewing the ABC variables as a less linear and more dynamic process, (Boss, 2002). However, in 2016, Boss modified her model to clearly identify the broader bio-social-psychological, cultural, and philosophical community constructs influencing ambiguous loss, boundary ambiguity and family stress (see figure 1).

Figure 1. The Contextual Model of Family Stress



Source: Boss (2016). The context and process of theory development: The story of ambiguous loss. *Journal of Family Theory and Review, 8,* 269-286. The figure is found on page 272. Used with permission. See Appendix J license for permission from John Wiley and Sons.

Illustrated in figure 1 the stressor event (the A variable) is the unique ambiguous loss situation. Boss stated (2002): “a stressor event is an occurrence that is of significant magnitude to provoke change in the family system” (p. 47). A stressor event disturbs the existing state of affairs of families and has the potential to increase families’ stress levels (Boss, 2002). Ambiguous loss, as a stressor event, is significantly powerful because it defies the resolutions families would have in a clear-cut death. The societal criteria for family boundary maintenance and the psychological construct of closure cannot be met (Boss, 2004, 2006). Ambiguous loss stressor events impact directly on the levels of stress and trauma experienced by individuals and families.

The B variable noted in figure 1 represents the individuals' families' resources and strengths during the time of the event. The B factor includes contextual resources internal to the individual and family; their internal coping, adaptation and resilience factors. Boss adapted the concept of family resilience from the arenas of psychological and family stress management. Boss (2006) uses the definition of family resilience provided by Hawley and DeHaan (1996) who stated: "family resilience describes the path a family follows as it adapts and prospers in the face of stress, both in the present and over time" (p. 7). Boss (2016), determined in relation to ambiguous loss, resilience has a specific meaning; increasing one's tolerance for ambiguity.

The perceptions of the situation of the ambiguous loss event by family members are the emphasis of Factor C in figure 1. Families develop perceptions about the definition of the event and family functioning. Family perceptions are tied to boundary ambiguity. Boss and Greenberg (1984) defined boundary ambiguity "as a state in which family members are uncertain in their perceptions (as individuals and or collectively) about who is in or out of the family and who is performing what roles and tasks within the family system" (p. 2). Role assignments can change or be ignored, decisions put on hold, daily tasks remain incomplete, and family members can be ignored or cut off. High degrees of boundary ambiguity correlate to higher degrees of incongruence between the psychological family (holding onto emotional bonds with loved ones) and the physical family (Boss, 2006). High boundary ambiguity can compromise individual and family wellbeing and erode resilience. Higher levels of boundary ambiguity are indicative of a risk factor that can lead to negative individual and family outcomes manifested through individual psychological symptoms i.e. depression, passivity, immobilization, and anxiety (Boss &

Greenberg, 1984). Boss operationalized the degree of boundary ambiguity through the development of empirical measurements (1984). Boss (2002) places particular emphasis on the C factor because individual and or collective family perspectives are highly powerful in determining outcomes.

Boss (2016) placed the concepts of trauma and stress into a different contextual meaning so that these concepts are now conceived as relational, not residing only within the individual domain (factor X in figure 1). Stress as defined by Boss (2006), “is a pressure of the status quo of a system…that is the system is no longer in a steady state” (p. 35), and trauma “is a stress so great and unexpected that it cannot be defended against, coped with, or managed” (p. 35). Boss (2006) contends that the degree of stress from an ambiguous loss event can be extremely unmanageable and traumatizing for the families experiencing the ambiguous loss.

The iterative essence of ambiguous loss theory is built on the following conceptual relational propositions:

- Phenomenon need not be measured to exist (Boss, 2016).
- An ambiguous loss event is required to consider degrees of boundary ambiguity and stress (Boss, 2002).
- How family members perceive the ambiguous loss stressor impacts on the degree of boundary ambiguity. “The higher the boundary ambiguity in the family system, the higher the family stress” (Boss & Greenberg, 1984, p.8).
- “The higher the family stress the higher the individual and family dysfunction” (Boss & Greenberg, 1984. P.8).
- “If a high degree of boundary ambiguity persists over time, the family system will become highly stressed and subsequently dysfunctional” (Boss & Greenberg, 1984, p.8).

- "Boundary ambiguity levels can decrease over time when family members can take in new information, and through a process of cognitively restructuring the meaning of the ambiguous loss event, stress can decrease and family resilience can be maintained and strengthened" (Boss & Greenberg, 1984, p.8).
- Not all situations of ambiguous loss lead to high boundary ambiguity (Boss, 2006, p. 12).
- To begin coping, families need the problem to be identified as ambiguous loss (Boss, 2016).
- "Community and culture also influence the perceptions of ambiguous loss, therefore the greater the ability of community to define boundaries as more flexible and open will lead to a decrease in the degree of stress and trauma" (Boss, 2006, p. 13).
- "The length of time a family will tolerate a high degree of boundary ambiguity is relational to the family's cultural context" (Boss & Greenberg, 1984, p. 9).
- Outcomes of ambiguous loss are attached to the attributions and belief systems of individuals, families, and communities (Boss, 2006).

Assumptions

Assumptions that underpinned the study were:

- ABI significantly negatively impacts the lives of individuals and families.
- ABI is an ambiguous loss event
- While people are individuals they are also a part of a family system and a person's feelings and behaviours are intertwined with and influenced by others in the system.
- Family narratives are built from reflecting on how they make sense of their world.
- Meaning making in the family is associated with family adaptations to stressful conditions.

- Families have stories that they are capable of telling and want to have heard about their lives with ABI.
- The needs of families are often ignored in favour of what is in the best interest of the person with the ABI.

The Researcher

The impetus and passion for this study arose from two avenues: my years of professional clinical practice work with individuals and families affected by ABI; and my own family's five-year experience of my husband's ABI, ending with his death over ten years ago. While I bring clinical skills, personal knowledge and insight of the whole context of the impact of an ABI event on individuals and families, I acknowledge these experiences could bias the interpretation of findings. In addition to my assumptions and theoretical orientation being made explicit, to further support trustworthiness I included the strategies of: triangulation of data, rich thick description, member checking, keeping an audit trail by documenting methods decisions, maintaining a reflexive journal to capture self-awareness, addressing the investigator role in co-creating the narratives, and discussing emerging themes with committee members.

Rationale and Significance

The rationale for this study arose from the voices of families affected by ABI indicating minimal supports exist for families and that health care professionals need to further acknowledge and attend to the entire family system and not just the individual and primary care giver (Boschen, Gargaro, Gan, Gerber, Brandys, 2007; Clark, 2009; Gan, Campbell, Gemeinhardt, & McFadden, 2006). While research has led to the development of specific ABI family intervention programs with positive results (Gan, Gargaro, Kreutzer, Boschen, & Wright, 2010; Kreutzer, Stejskal, Godwin, Powell, & Arango-Lasprilla, 2010), increased understanding, of families' experiences acquired through this study can positively impact on a continuum of family centered practice.

Definitions of Key Terminology Used in This Study

ABI – A generalist acronym that refers to damage to the brain which occurs after birth. There are two brain injury categories: 1) a traumatic brain event (TBI) resulting from a motor vehicle collision; fall; assault or sports injury; 2) or a non-traumatic brain event (nTBI) such as stroke; aneurysm; infection of the brain and or a tumour (Cloute et al., 2008; Fraas & Calvert, 2009; Rosenthal & Ricker, 1999). Genetic disorders; developmental disabilities (e.g. Down's syndrome); or diseases which progressively damage the brain (e.g. Alzheimer's, multiple sclerosis) are not considered to be an ABI (Murray, et al., 2006) .

Family - As both the individual and family members will be participants, for the purpose of this study, 'family' will be defined as the family is who they believe themselves to be "a self-defined group of individuals" (Eggenberger & Nelms, 2007, p.284).

Ambiguous Loss – Ambiguous loss is defined in two ways: 1) a loved one is physically missing yet kept psychologically present; and, 2) a loved one is physically present but psychologically absent (Boss, 1999). In definition one this physical absence could be a result of war, terrorism, ethnic cleansing, genocide, kidnapping, natural disasters and unnatural causes. Conversely, examples of the second type of ambiguous loss include people living with Alzheimer's disease, dementia, brain injury, AIDS, autism, depression, addiction, or other chronic mental or physical illnesses (Boss, 2006).

About Writing Style

I will use the first person on occasion throughout this thesis, which is considered acceptable for qualitative research. According to APA format (American Psychological Association, 2010), first person may be used when describing research procedures and when referring to self as the researcher.

Chapter Two: Literature Review

In this literature review about families' experiences with an ABI event, the significance of the impact on experiences of loss for individuals and families was explored. However, since families have been recognized as a specialized area of study (Nye, 1988), this chapter begins with an overview of the definitions of family and family research. This will be followed by a critical review of empirical literature on current knowledge about ABI and loss and reactions to loss for individuals and families. The initial critical review began prior to the start of the study and was updated in 2019 to include further relevant literature. Concluding this chapter is an analysis on how the extant research informed the study, and how the study addressed the limitations identified through the literature. Through this exploration of the literature about ABI and loss it is clear that research elucidating 'whole' families' perspectives of the impact of an ABI event continues to be a critical next step in building knowledge about this experience that can be useful for informing family centered practice.

Defining Family

Defining families is challenging as they can be viewed as biological, legal, structural, and functional systems (Astedt-Kurki, Paavilainen, & Lehti, 2001). Concepts of family as a regulated social institution have evolved over time and continue to be debated (Marcellus, 2006). Traditionally, in North America, families generally have been conceptualized to mean the nuclear family unit; married mother and father living with their biological children (Marcellus, 2006, Munford & Sanders, 2003). However, as social relations became more diverse, families redefined themselves by moving beyond the definitions of nuclear and extended (Farias & Asaba, 2013). Single parent and blended or step families are prominent. Families created from lesbian and gay, two spirited, queer, and transgendered community networks are also being recognized within the landscape of conceptual family frameworks (Muraco, 2006). Families can also be conceptualized according to life cycle and developmental categories and through the personal perspectives of researchers (Munford & Sanders, 2003). To acknowledge these reconceptualizations, Kean (2010) defined family "as a group of persons who share a history and a future and are committed to each other" (p. 67). The Canadian Nurses Association (1997) "considers a family as those persons who are identified by the client as providing familial support, whether or not they are biologically related" (p.2). Wright & Leahey (2009) determined the family is who they believe themselves to be. Giving the concept of 'caring' legitimacy in the family construct, de Vries (2010) argued families are being created through "a constellation of caring relationships that lay well beyond the traditional parameters of family connectivity" (p. 1). Families are now choosing individuals (friends) to be part of the family sphere. This particular premise is noted in the definition provided by Hartrick Doane and Varcoe (2005): "Families are a complex process where economics, emotion, context, and relational experience are interwoven and multilayered" (p. 43). The perspectives of what constitutes family are inclusive of the range and diversity of families in contemporary society.

Defining Family Research

Across disciplines the challenge in researching families has been the need to differentiate between *family-related* research and *family* research. *Family-related* research focuses on the individual's attributes and perceptions within the family while *family* research is concerned with studies that involve the family unit (data collection from two or more family members) (Feetham, 1984; Moriarty, 1990). Therefore, *family* research is viewed as research with the family as a whole; meaning family as a group is the unit of analysis (Feetham, 1984; Marcellus, 2006). Alternatively, Robinson (1995) argued for a re-conceptualization of the term family as the unit of analysis to include *both* the individual family member and the family. This integrated perspective eliminates the decision to research either the individual or the family by placing both the individual as family member and family in the foreground. This allows for both the individual and family system to be studied together (Robinson, 1995). Robinson (1995) designated this conceptualization – “individual/family system” (p.20) unit of analysis.

An associated issue in defining family research has been the ongoing incongruences between what has been labelled as family research and the form taken for the research design. Ganong (2000) noted this issue by contending that the boundaries between family-related research and family research are blurred due to the inconsistencies in the unit of researcher interest, unit of measurement and the unit that is analyzed. In other words, the intent of a researcher to study the family unit is often thwarted by their choice of data collection strategies and methods of data analysis that focus on obtaining information only from an individual family member. Consequently, upon further review, research labeled as ‘family research’ may only be considered as family-related research (Ganong, 2000). Earlier, Fisher (1982) recognized this issue and, in an attempt to resolve this dilemma, he devised a framework for investigating family phenomena based on three types of data collection strategies: individual, relational, and, transactional. Fisher (1982) conceded “most researchers designate the person, who also happens to be the family member, as the object of study and not the family as a unit” (p.1). The individual level data collection strategy supports the tendency towards having the individual represent the family (Fisher, 1982). Individual level data is collected from a single family member with a particular family role (i.e. mother, father, and child) (Sullivan & Fawcett, 1991). The data collected from the individual respondent reflects only their views about their behaviours and perceptions of other family members’ attitudes, actions and beliefs (Fisher, 1982; Sullivan & Fawcett, 1991).

Individual perceptual data does not reflect the family entity and cannot be viewed as whole family data (Sullivan & Fawcett, 1991). Relational level data collection is obtained from two or more family members and reciprocally linked by the researcher through various data analysis methods (Fisher, 1982; Sullivan & Fawcett, 1991). Relational level data is only a representation of the family rather than data derived from actual family interactions (Sullivan & Fawcett, 1991). Fisher (1982) coined the term 'transactional' to denote the interrelatedness and characteristics amongst the family as a whole allowing the data at the transactional level to be a "product of the system… significantly different from the sum of its parts" (Fisher, Kokes, Ransom, Phillips, & Rudd, 1985, p. 2). Transactional level data collection can only be generated through discernable interactions amongst multiple family members (Fisher et al, 1985; Sullivan & Fawcett, 1991). Multiple family interviews are a useful way to add more depth to the data collection process (Astedt-Kurki, et al., 2001). Data from both the individual and family members is deemed necessary to provide greater understanding of the phenomenon of ABI with family (McClement & Woodgate, 1998). In summary, in order to initiate a critical review of the literature on families' experiences with an ABI event, it is important to set the context for the definitions of family and family research as these will provide a future guiding analytical lens.

The Review Process: Empirical Literature

To access the empirical literature the following online data base search engines were used: CINHAL; Family and Society Studies Worldwide; ProQuest; PsycINFO; PubMed; Scopus; Social Sciences Citation; Social Services Abstracts; Sociological Abstracts; and Social Work Abstracts. Key words used to search the databases included: *brain injury; acquired brain injury; traumatic brain injury; experiences; individuals; families; family systems; loss; ambiguous loss; and unclear loss*. In addition, the search also included speciality organizations on the World Wide Web such as: Brain Injury Centre Canada; The Brain Injury Society of Toronto; Brain Injury Association of Waterloo-Wellington; Manitoba Brain Injury Association; and the Manitoba Public Insurance Corporation. The review process begins with the ABI and loss literature concerned with the adult survivor looking at the types of loss experienced and related issues. Next, I provide an in-depth analysis of the ABI and loss literature related to family experiences by looking at the particular family subsystems that were studied.

ABI and Loss: The Individual

Loss is a universal formidable human condition. Loss can be connected to normative life cycle transitions such as human development and aging (McGoldrick, Heiman, & Carter, 1993), however, it is most often associated with adverse life events: traumatic events, death, disability, chronic illnesses, substance abuse, unemployment, relationship failure, and educational defeat (Murray, 2001). The concept of loss signifies the loss of something believed to have been meaningful or of value and is associated with grief; the emotional response to loss (Murray, 2001; Nochi, 2000). Loss is a psychosocial phenomenon and corresponding sequelae are often categorized within the realms of: altered functioning, decreased quality of life (QoL), and wellbeing (Dijkers, 2004; Murray, 2001). The loss of capacity and functioning have been described as the center of loss for those living with an ABI (Murray, 2001; Roundhill, Williams, & Hughes, 2007). The loss of capacity includes physical, cognitive and emotional functioning (Fraas & Calvert, 2009; Jones et al., 2011; Jumisko, Lexell, & Söderberg, 2009; Nochi, 1997). These often can be accompanied by a secondary set of felt losses: self-esteem and self-worth, sense of ‘being’, social and relational, and control (Murray, 2001; Tasker, 2003). In a completed review of Quality of Life (QoL) research after a traumatic brain injury the majority of QoL losses as expressed by individuals, determined through qualitative and quantitative methodologies, were loss of: employment; education; income; intimate relationships; work relationships; friendships; quality of family relationships; roles i.e. as a spouse, provider; leisure activities; general health; mental health; and self-awareness (self-identity) (Dijkers, 2004).

Loss of capacity and functioning are also described as hidden as some brain deficits are not readily ‘seen or visible’ and dependent on the level of severity of an ABI, the resulting changes in an individual can manifest themselves differently in every person (Alston, et al., 2012; Chamberlain, 2006; Freeman et al., 2014; Lorenz, 2010). To the casual observer hidden losses are not obvious, thereby giving the impression that the individuals with the ABI are ordinary and functioning without a disability (Alston et al., 2012; Chamberlain, 2006; Lorenz, 2010). Therefore, head injured persons can be victims of a societal devaluing and stigmatizing; another form of loss. Within the realm of loss of capacity and functioning the issue of the loss of self has become a significant area of research from which considerable knowledge has been derived.

Loss of self. Stemming from a medical and neuropsychological view, early brain injury rehabilitative research exploration was primarily concerned with determining how the brain injury affected the self-awareness of individuals (Nochi, 1998). Nochi’s use of narrative as a method of inquiry to examine the subjective loss of self (awareness and or identity) was part of a shift to research how people with ABI understood and defined themselves and their experiences from their own distinct perspectives (Nochi, 1998 a;1998 b; 2000; Nochi, 2010). Nochi (1998) developed three typologies of how this lost self is experienced: “loss of clear self-knowledge; loss of self by comparison, and loss of self in the eyes of others” (p. 875). In his seminal work, Nochi (1998) was able to distinguish levels of loss of self, involving the complex context of memory loss prior to the ABI, differing pre and post self-images, and socio-cultural messages of not being the same self. Nochi demonstrated that even years after the original brain injury such individuals continued to indicate: major difficulties sorting out what they were not capable of doing; ongoing comparisons between pre and post injured selves all the while continuing to mourn their pre-injured self; and being labeled as brain injured negated their sense of self. Since Nochi, other researchers studying individuals' experiences of an ABI have further added to the body of knowledge on the loss of self-identity.

Vickery, Gontkovsky, and Caroselli (2005) investigated the relationships between sense of self, depression, and QoL with 19 participants whose average age was 30.5 years and were 36.5 months following a severe traumatic brain injury (TBI). Using a series of measurement instruments, Vickery et al. (2005) suggested that a less satisfied sense of self is associated with mild levels of depression and emotional distress impacting on their overall QoL. Heller et al. (2006) applied a multidimensional perspective to Nochi's three typologies of the lost self. From this perspective the brain injured self is composed of multiple selves, each self, playing a part in the identity of the survivor. According to Heller et al. (2006), the brain injured individual has a "theater of possible selves" (p. 48) and these possible selves interact with each other and the greater environment. Heller et al.'s (2006) work provides an alternative pluralistic perspective on the sense of self post brain injury.

Using a larger participant sample (32 participants vs the ten participants in Nochi 1998) and small group interviews, Gracey et al. (2008) confirmed that loss of identity is a significant theme for brain injured individuals. In their metasynthesis Levack et al. (2010) identified a substantial body of qualitative research on the lived experience of ABI survivors reflecting key identity issues including: the loss of personal identity, loss of bodily connection and control, and loss of a place in the world. In a scoping review on occupational and self-identity after a brain injury, Bryson-Campbell et al. (2013) also highlighted loss of identity as a key issue following a brain injury.

Gender differences. It has been recognized in the literature that because of the greater incidence of ABI with males, women's experiences of brain injury have often been ignored (Howes, Benton, & Edwards, 2005). To address this gap Howes et al. (2005) explored the ABI experience through the perspectives of six women survivors who had received a TBI, ranging from mild moderate to severe, seven months to 15 years post injury. Themes that emerged related to loss of self were awareness of change and the struggle to make sense of their lives (Howes et al., 2005). The findings from Howes et al (2005) paralleled the themes identified by Levack et al. (2010), with one notable exception. These women associated weight gain or loss as a significant factor towards their sense of self; distinguishing body image as an important variable for women's loss of self. An Australian study also prioritized the experiences of 11 traumatically brain injured women (Alston et al., 2012). Recognizing the dominant identity issues for women were coming to terms with a new sense of self and body image, Alston et al's (2012) findings further demonstrated the differential losses for women which included: loss of control and power, loss of psychosocial supports, and loss of socialization making women more vulnerable to abuse and less likely to have a care giver person.

More recently, the literature has again highlighted the need to further address research, knowledge and clinical gaps on the impact of brain injury on girls and women (Colantonio, 2016). In a systematic review, Oyesanya and Ward (2016) determined more research is required on understanding the mental health issues for women with TBI, particularly depression. Haag et al. (2016) completed a unique qualitative study focusing on the influences of sex and gender on women's' health and well-being after ABI. Their thematic findings demonstrated how the social construct of gender contributes to women's experiences of living with ABI (Haag et al., 2016). Using data from a women's ABI self help group and drawing from gender- based analysis, Gelech, Bayly and Desjardins (2019) argued within a gender segregated treatment environment, women were able to "construct competent selves; temper the threat of loss and impairment; resist infantilisation and delegitimisation; and assert a collective gender identity" (p. 468).

Adding to the knowledge of loss of self in the eyes of others as developed by Nochi (1998), Freeman et al. (2014) further explored the lived experience of nine traumatic brain injury (TBI) male survivors in relation to perceived changes to their social identity and focusing on men's' emotional responses. The themes of perceived changes to their social identity: sense of abnormality; hidden injury; others treat me differently; and the old me –new me led to the corresponding emotional responses of self-criticism; need to be as others want me to be; withdrawal from my social world; and resolution in positive growth (Freeman et al, 2014). In summary, these studies on loss and gender highlight the need to continue to further examine how social constructs of gender impact differently on individuals' perspectives of self, post ABI and potential treatment modalities.

Associated emotional grief reactions. While studies have reported on the emotional suffering (grief, regret, fear, anxiety, loneliness, anger, self-blame and guilt) experienced by TBI participants (Levack et al., 2010), overall, the literature is limited when specifically addressing the emotional suffering associated with the loss of self, following a brain injury (Filhour, 2017). One mixed methods study exploring the experiences of 60 individuals one-year post TBI concluded: TBI sufferers' grief processes do not follow a normal linear time determined framework; rather their grief is a complicated process of being constantly reminded of the loss of self, therefore grief is cyclical and repetitive (Chamberlain, 2006). Employing a qualitative approach with seven individuals (six males & one female) with a severe TBI two years post injury, Roundhill et al. (2007) investigated grief reactions underpinned by the Dual Process Model. According to Roundhill et al. (2007), the Dual Process Model differs from more traditional grief models, proposing for a loss to be accommodated, the pain of grief needs to be worked through. These results are significant because they demonstrated TBI individuals experienced a more oscillating non-linear approach to grief as their degrees of denial and avoidance were considered to be an integral part of adjusting to the loss of self (Roundhill et al., 2007).

Reconstructing self. Adjacent to the investigations on understanding the subjective loss of self, researchers have been exploring recovery and rehabilitation through the question: How do individuals with an ABI rebuild and or reclaim their lost sense of self? The findings from Miner's (1996) hermeneutic exploration of a 27-year-old woman who had experienced a severe brain injury at the age of 16 suggested that alongside the initial recognition of the loss of self is the process of finding meaning for one's life for the purpose of reincorporating the self.

Nochi (1997) further advanced the premise that ABI survivors' construction of meaning correlates to the reconstructing of the self. Nochi (1997) analyzed narratives from four individuals with a TBI who had long term memory issues. Nochi (1997) noted the participants' narratives suggested that they experienced a void in understandings of their past and present and to deal with this void they pieced together stories about themselves from interactions with people and the world around them. Nochi (1997) reached a similar conclusion to Miner (1996); in order to make sense of themselves these individuals needed to construct a meaning for their lives. The revising of self–image is again explored in Nochi's (2000) qualitative study with 10 individuals with TBI (three to twenty-eight years post injury) who thought they were coping with their changed lives. According to Nochi (2000) the thematic findings of: "the self better than others; the grown self; the recovering self; the self-living here and now; and the protesting self" (p.1795) reflected the building of meanings led to a renewed view of the self. In his research Nochi (2000) emphasized acquiring meaning for the reconstruction of the self is a reciprocal series of interactions with others, society and culture. This perspective was upheld by Gracey et al. (2008). Using a small group design with 32 individuals to explore how people make sense of themselves after a brain injury, Gracey et al (2008) concluded that the reconstruction of self is determined through an integration of social context and subjective experience. Nichols and Kosciulek (2014) used a grounded theory approach with seven participants (24-55 years of age – at least nine months post brain injury) to explore social interaction experiences, and deduced also that identity post brain injury is shaped by the social interactions with significant others.

Compared to Miner (1996) and Nochi (1997), Inkmann's (2001) research is unique given the focus on participants with mild brain injury. Based on the stories by two women and three men about their pre and post brain injury experiences, Inkmann (2001) reported that while these individuals initially described their lost self as a 'shattered self' they were able to discover meaning that allowed them to adapt, grow and evolve an identity; helping them to heal emotionally and psychologically. Inkmann's study (2001) adds to the empirical research positing the construction of meaning is critical for the reconstruction of the loss of self. Tasker (2003) extended the research on meaning making by highlighting the concept of spirituality within the meaning making process. Jumisko et al. (2009) further proposed that for people with moderate or severe TBI finding an identity is reconciled with meanings surrounding the concept of feeling well involving accepting themselves and renewed connections with others. In a large quantitative study involving 630 participants, Jones et al. (2011) concluded individuals with a severe brain injury were more likely than those with less severe injuries to engage in significant identity work creating meaning towards cultivating a survivor identity rather than a victim identity.

Lorenz (2010) proposed a new theoretical framework to conceptualize the process of building a post-injury brain identity. Lorenz (2010) suggested this process has three stages:

> In the first stage, the old self is lost and is dominated by the new, brain – injured self. In the second stage, the old self and the new self engage each other, resist each other, and begin to find a balance. In the third stage, the old self and the new, brain-injured self are members of a multiplex of selves that accept each other and alternate in precedence, depending on the survivor's context (e.g., doctor's office, home, work environment. Support group, stress level, and health status at any given point). (Lorenz, 2010, p. 152)

Lorenz's (2010) typology of the multiplicity of selves is akin to the perspective espoused by Heller et al., (2006) of the pluralistic sense of self. However, Lorenz's (2010) typology can be viewed as a continuation of the pathological paradigm; failure to move onto the next stage is negatively judged.

The previous literature reviewed is dominated by the discourse of the construction of self as either being fully 'lost and or shattered' or gaining a balance (Gelech & Desjardins, 2011). Gelech and Desjardins (2011) argue this dominant discourse is very limiting. Another narrative was put forward in Westcott's (2007) hermeneutic phenomenological study with six participants. According to Westcott (2007) what surfaced following a TBI were narratives about shifting identities which were being constantly negotiated through lived experiences and in relationship with others. Gelech and Desjardins' (2011) narrative research using a life history approach with three men and one woman (ranging in age 37-55, four-21 years post ABI injury) continued with the exploration of other narratives. Gelech and Desjardins' (2011) research findings, similar to the research of Medved and Brockmeier (2008), determined individuals have a strong sense of a continuous self and they resisted the lost self view of the post injury selves because it was never lost. The sense of shifting and continuous selves derived from the notable work of Westcott (2007), Medved and Brockmeier (2008) and Gelech and Desjardins (2011) provides researchers and health care professionals with an alternative lens from which to develop different service interventions. However, it is unclear in the literature whether the premise proposed by Westcott (2007), Medved and Brockmeier (2008) and Gelech and Desjardins (2011) are being further advanced as Bryson-Campbell et al. (2013) in their scoping review on self-identity affirmed the dominance of the theme of loss of self. However, recent research from Gendreau and de la Sablonnière (2014) may suggest otherwise. In studying the cognitive process of identity reconstruction in individuals with an ABI or spinal cord injury their findings yielded a less static unidirectional three-stage heuristic process of identification with the pre-injury self, moving towards recognition of new identity characteristics, and potentially culminating in identity integration and the need for continuity of self throughout life (Gendreau & de la Sablonnière, 2014).

ABI, loss, the individual and treatment. Although there is an abundance of scientific literature on rehabilitation strategies and treatment methods with individuals living with an ABI, there has been a noticeable turn in the rehabilitative literature acknowledging health carer interactions with individuals affected by ABI are mitigating influences on the impact of the ABI trauma and identity issues. Client-centred approaches to care are coming to the forefront as recognition of individuals' inherent abilities to effectively problem solve and make decisions has increased (Black, 2005). While theoretical articles espouse the need to implement client-centered care; a practice of respect, collaboration and partnering with individuals receiving health care (Law, Baptiste, & Mills, 1995); there is minimal research evidence of the implementation of client centered approaches and the impact on clients. In their research of client perspectives of client-centered care, D’Cruz, Howiea & Lentin (2016), affirmed that a person-centered approach to engagement and interactions provided positive emotional support to the individual struggling with changes to their identity following an ABI. In a narrative qualitative study about how ABI patients experience health care relationships and decision making, Wright, Medved, Woodgate, Roger, and Sullivan (2016) determined patients need meaningful relationships with health carers based on respect, valuing, and understanding to help with their recovery. This turn in the literature to a focus on relationships with health care professionals as an instrument for caring highlights connections with others impacts on individuals experiences of ABI and loss.

Summary of ABI, loss and the individual. The empirical literature on ABI and loss for the affected individual family member has established survivors’ experiences have been substantially captured and through the analysis of this body of knowledge there are several noteworthy findings. The acknowledged demographics included adults of varying ages, degree of injury, type of injury (traumatic or non-traumatic) and years post injury. The knowledge acquired is primarily derived from a substantial body of qualitative research using various methodological approaches and methods. Notwithstanding these differences there appears to be uniformity in the findings. The themes of loss experiences, pivoted on the loss of self, are encompassing, perpetual, developmental and nonlinear. The findings also suggest there are differential loss experiences between the genders. However, this important body of knowledge highlights this research has been focused on the individuals’ perceptions of their bio-psycho-social world. By continuing to collect individual level data, knowledge of how the interrelationships and interconnections with others would have on impacting individual loss experiences is largely still missing.

ABI and Loss: The Family

The research turn towards recognition that families were also affected by brain injuries began in earnest in the 1970's (Sander, 2007) with the major acknowledgement that brain injury occurs within the family context (Dell Orto, & Power, 2000). As the science regarding the impact of ABI on families emerged, important knowledge unfolded. Families were called the second victim (Rosenthal & Ricker, 1999) and reported the ABI, once it had occurred, was something which "continued to permeate their lives, to the very core, and remained the single most significant characteristic of their existence by which they defined all future life experiences" (Leith et al., 2004, p. 1204). While the impact trajectory of ABI begins with healing from initial injuries and in time shifts to coping with a chronic illness, unlike other chronic illnesses the effects do not lessen over time (Braine, 2011).

Neurobehavioural sequelae are no less daunting for families than individuals. The greatest challenges facing families are the neurobehavioural alternations of their loved one, such as: reduced empathy and increased self-centered behaviour; reduced self-regulation and increased impulsiveness and silliness; decreased executive functioning; increase or decrease in sexual activity; and difficulty with social learning: resulting in various degrees of personality and psychosocial changes (Lezak, 1978, 1988; Segev, Levinger& Hochman, 2018). These alterations to the cognitive, emotional behavioural, and personality of the affected individual family member are what make the challenges and experiences of loss distinctly different for these families than other families affected by long term chronic disabilities (Florian et al., 1989; Jackson, Turner-Stokes, Murray, Leese, & McPherson, 2009). Often these neurobehavioural changes are hidden from view of family members. This invisibility generates the families' perception of the affected family member as not being the same person (Webster et al., 1999). The psychosocial ramifications of ABI on families has largely been described as negative and long-term with: increased levels of burden and responsibility of care for families over time; continued exposure to prolonged stress and strain and stress related to daily coping; and harmful effects on families' social, emotional, structural, and financial functioning; role changes; and challenges to core values and resources in families (Brooks, 1991; Florian et al., 1989; Lezak, 1988; Mauss-Clum &Ryan, 1981; Christensen et al., 1997; Degeneffe, C., 2001; Dell Orto, & Power, 2000; Kosciulek & Lustig, 1999; Webster et al., 1999). The state of the current knowledge describing the impact of an ABI event on families' experiences of loss and psychosocial challenges will be summarized and critically reviewed in the following sections. These sections have been organized according to the manner in how families have been studied.

Primary Family Member and or Caregiver

Once discharged from a hospital setting the ABI survivor often returns to a family unit. As families attempt to cope with changes in their loved ones, families face considerable burdens and responsibilities regarding the provision of direct physical, emotional and instrumental assistance to the brain injured member (Allen, Linn, Gutierrez, & Willer, 1994). The family member most likely to assume these caregiver responsibilities and influence family functioning are spouses and parents (Gan, er al., 2006; Livingston et al., 2010), and as males are more prone to ABI events, women are more often in the role of primary caregiver (Zeigler, 1999). Recently, research with caregivers has further subdivided the role, investigating possible differences between primary and secondary caregivers (D'Ippolito, et al., 2018). Differentiating between the two, D'Ippolito et al. 2018 described primary caregivers as spending "most of the time with the patient, providing daily care and taking most responsibility for the day-to-day decisions, while secondary caregivers are those who provide additional support" (p.1).

Often caregivers are providing support without adequate professional assistance and intervention (Degeneffe, 2001). Much of what is known about the psychosocial effects and corresponding issues of loss on families has been derived from examining the experiences of caregivers. As a result, caregivers continue to garner considerable attention in the literature with a large body of carer research literature centered on experiences of female caregivers as a result of adult male ABI survivors (Conoley, & Sheridan, 1996).

Impact of survivor neurobehavioural changes on caregivers. Empirical evidence consistently reports the negative impact of survivor neurobehavioural changes on caregivers. Findings suggest: aggression, depressive symptomatology, forgetfulness, apathy, constant neediness, memory impairments, and impeded abilities to carry out basic tasks, motor dysfunction, illicit drug use, lower functioning at rehabilitation discharge, are all predictors of increased carer stress, strain and burden, diminished quality of life (QoL), life satisfaction and well-being (Boycott, Yeoman, & Vesey, 2013; Jackson et al., 2009; Livingston et al., 2010; Mauss-Clum, & Ryan, 1981; Minnes, Graffi, Nolte, Carlson, & Harriack, 2000). The research findings of Wells, Dywan and Dumas (2005) determined not only did behavioural disturbances have a negative effect on the life satisfaction of caregivers but also negatively influenced their levels of coping. Their research findings are significant because participant criteria spanned one-40 years post injury and included a range of brain injury diagnosis form mild to severe (Wells et al., 2005). These ranges are much broader than most other participant criteria which usually involve moderate to severe injury level and one-five years post injury. A more recent study continues to provide evidence of the negative impact of survivor neurobehavioral changes on caregivers. Results from data collected by caregivers, who completed The Caregiver Burden Scale of Life Satisfaction at time markers of post ABI at one and two years, concluded there was an increase in caregiver burden and decrease in life satisfaction at two years post injury compared to one year (Manskow et al., 2017).

Carers' perceptions of and reactions to loss. Investigators using quantitative methods have examined carers' individual perceptions of loss and psychological reactions. In their seminal quantitative pilot study with wives and mothers of brain injured survivors (at least six months post injury), based on survey responses, Mauss-Clum and Ryan (1981) found these women were experiencing levels of emotional reactions that included: frustration, anger, irritability, and depression. As well, the women reported experiencing decreased time for themselves, financial insecurity and grieving the loss of their husbands because these men were not the same husband and person as before the ABI event (Mauss-Clum & Ryan, 1981). Even though these results were based on a small sample size of 30 respondents, Mauss-Clum and Ryan's findings can still be considered valid as further exploration of emotional and mental health issues with larger participant numbers has substantiated that carers can develop clinical symptoms of depression, anxiety, somatization, mania and post-traumatic stress (Heinlen, 2006; Rivera, Elliot, Berry, Grant, & Oswald, 2007). In an even larger study situated in Guadalajara Mexico, the mental health of 90 family caregivers of individuals with ABI was compared to 89 participants of an age-matched healthy control group. To ascertain participants' levels of mental health outcomes measures assessed satisfaction with life, depression, social support, self-esteem, and anxiety (Perrin et al., 2013). Overall findings suggested ABI caregivers reported substantially lower mental health scores across all indices; in particular, the effect sizes for three indices, satisfaction with life, self-esteem and state of anxiety reached large size effects of over 0.80 on the Cohen's *d* (Perrin et al., 2013).

In one of the few qualitative studies to explore caregiver challenges following an adult family members' ABI, thematic findings indicated carers were experiencing: significant stress of uncertainty about the loved ones' current condition, a variety of intense emotional responses, and the burden of decreased loss of personal time as everyday life patterns were changing (Piyakong, 2014). These noteworthy findings, gathered from carers whose family members were still unconscious in a critical care setting in Thailand, highlight the early onset of loss and psychosocial experiences and the possible homogeneity of these experiences.

Caregiver coping. An important consideration in understanding the impact of ABI on caregivers and their families is the heterogeneity of coping characteristics, skills and resources family caregivers possess as coping efficacy can significantly affect psychosocial and psychological experiences of carers (Degeneffe, 2001). One aspect of understanding how carers cope and adapt has centered on examining the subjective perceptions of stress and burden through assessing the component of appraisal. Appraisal measures target the subjective emotional and cognitive perceptions of carers (Hanks, Rapport, & Vangel, 2007).

Grounded in the stress appraisal coping model, the research by Harris, Godfrey, Partridge and Knight (2001) evaluated the role of appraisal of environmental demands, personal and social coping resources in predicting caregiver emotional coping. The findings from 58 carers suggested perceived adverse effects on other family members were the significant predictors of greater degrees of caregiver depression (Harris, et. al., 2001). Their findings also proposed better carer adjustment occurs when carers: regard the ABI problems to be less threatening, utilize problem focused coping, and when practical and effective support is available (Harris et al., 2001). In comparison, Hanks, et al. (2007) studied positive and negative appraisals of caregiving in the areas of perceived burden, relationship satisfaction, caregiving beliefs, and mastery in the role of caregiving. The results from 60 primary caregivers highlighted that positive appraisals of caregiving burden; relationship satisfaction and sense of mastery are moderately to strongly correlated with high levels of social support and family functioning (Hanks, et al., 2007). Also, caregivers who relied more on task-orientated coping verses emotion focused coping experienced better relationship satisfaction (Hanks, et al., 2007). Interestingly, Hanks et al. (2007) found the range of moderate to severe ABI injury was not a factor in carers' appraisals.

Kershner-Rice's (2011) quantitative study focused on the coping processes utilized by 48 caregivers in relation to life satisfaction. Three variables were determined to be significant to caregiver life satisfaction: 1) those who identified as the primary carer reported lower life satisfaction; 2) carers who provided fewer kinds of care described greater life satisfaction; and 3) viewing the caregiving situation as controllable or uncontrollable impacted on their perception of life satisfaction (Kershner-Rice, 2011). Also in examining the three forms of coping (problem-focused, emotion-focused, and meaning-focused), none of them were found to significantly predict caregiver life satisfaction (Kershner-Rice, 2011). It is interesting to note; this result varies from the findings of Harris et al. (2001) and Hanks et al. (2007). In a larger study involving 123 family members of which 63% identified as the primary caregiver, Carnes and Quinn (2005) also investigated the variables that facilitate family adaption following an ABI event. This study is unique for the use of the family adjustment and adaptation response model developed by McCubbin and Patterson (Carnes & Quinn, 2005). This model proposes that multiple factors interact to contribute to family adaptation to crisis (Carnes & Quinn, 2005), and in this case the crisis is the ABI event. Carnes and Quinn (2005) used various measures to determine factors that impact on caregiver psychological distress and family functioning. Results from bivariate analysis demonstrated significant positive correlations ($p < .01$) related to social support, decreased psychological distress and increased family functioning Carnes & Quinn, 2005). Overall, their findings indicated social and spiritual supports, financial stability, reframing, and higher premorbid relationship qualities impacted positively on the psychological health of carers and family functioning (Carnes & Quinn, 2005). Qualitative findings from a mixed methods research project with 50 Chinese primary caregivers has contributed further knowledge about the coping methods of families (Man, 2002). The findings highlighted positive coping was connected to empowerment components of: skill enhancement; actively seeking information and solutions; reliance on internal and external supports; and an overall sense of mastery (Man, 2002).

Caregiver needs. Researchers inquiring into the needs of carers and family members living with ABI have relied on caregiver informants. Over the years, quantitative studies, exploring family needs ranging from two to over 12 years post moderate –severe brain injury and using a variety of measures, have consistently identified a common subset of family needs. Carers have uniformly reported throughout the duration of caregiving the family need for medical and health information has most often been met, while the family need for emotional and instrumental support has most often been unmet (Doyle et al., 2013; Jumisko, et al., 2007; Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Murray et al., 2006; Rotondi, Sinkule, Baker, & Moldovan, 2007; Serio, Kreuytzer, & Gervasio, 1995; Witol, Sander, & Kreutzer, 1996). Findings from one particular quantitative research, informed by the theoretical framework of the stress process model of caregiving, found needs continued to change and evolve dependent on the stage of caregiving (Dillahunt-Aspillaga et al., 2013). In a singular qualitative study, carers discussed the need to also be empowered and have human connectedness and social belonging (Leith et al., 2004). Findings from a systematic qualitative review reported ABI patients and their caregivers felt the transition between hospital to home was not satisfactory; deficiencies mentioned included: communication, engagement, appropriate information and discharge community support (Piccenna, Lannin, Gruen, Pattuwage, & Bragge, 2016). Corresponding to family needs, studies have reported: health care services are fragmented and lacking in community-based programs following discharge from acute care settings (Leith et al., 2004; Mosconi, et al., 2011); health personnel can have fatalistic attitudes (Leith et al., 2004) and services are not accessed even when available (Murray, et al., 2006). According to a more recent Australian qualitative study, Kitter and Sharman's (2015) findings suggest care givers' quality of life is dependent on whether their support needs and the support needs of their loved one with ABI have been met. Consistent with previous literature, health care services were determined to be fragmented and insufficient throughout the recovery spectrum (Kitter & Sharman, 2015). The research by Kitter and Sharman (2105) suggest there is a global context to the needs of caregivers. Interestingly, the results of a qualitative study that explored caregiver involvement in an adult inpatient rehabilitation program, found participants struggled to maintain a balance between their engagement with the rehabilitation program and other life responsibilities; thereby compounding experiences of stress and burden (Savage & Egan, 2018).

Spouse and parent carers. Evidence about possible differences between the experiences of spouse and parent carers; remains inconclusive. After investigating 60 spouses and 71 parent caregivers of primarily severely brain injured persons it was determined there were more similarities than differences of experiences of burden between parents and spouses (Allen et al., 1994). However, other findings indicated different types of relationships (spouse or parent) create different types of burden on the carers; as spouses are likely to experience more significant role changes and financial and emotional burdens while parents are more likely to express concerns about the long-term futures of the brain injured person as it relates to issues of dependence and independence (Curry, 2006; Perlesz, Kinsella, & Crowe, 1999). In a quantitative study examining the psychosocial and psychological functioning of 62 caregivers of adult ABI outpatients, overall, caregivers reported elevated levels of distress, anxiety and depression; while spouses were significantly more likely to be depressed than parents (Kreutzer, Gervasio, & Camplair, 1994). Spousal caregivers also described greater diminished family functioning relative to parental carers (Kreutzer et al., 1994). As well, this study further supported evidence suggesting the strongest predictor for carer wellbeing was the number of neurobehavioural changes reported, particularly behaviour changes (Kreutzer et al., 1994). In a qualitative study examining both parent and partner caregivers' descriptions of their quality of life following an ABI, while several themes related to caregiving were similar, significant differences were found (Kratz, Sander, Brickell, Lange, & Carlozzi, 2017). Parental carers expressed greater grief and sadness related to the loss of their child post ABI; worried more about the future; and related feeling bound to their loved one (Kratz et al., 2017). Partners expressed greater burden, stress, guilt and loneliness related to shouldering the caregiving and decision making (Kratz et al., 2017). In comparison, a quantitative study targeting patient-caregiver pairs, found when caregivers were the son or spouse perceptions of the emotional and physical burden were stronger, while scores related to burden decreased in other kinds of family relationships (Maggio et al., 2018). The authors suggest there is an inverse relationship between caregiver burden and family functioning (Maggio et al., 2018).

Pediatric ABI parental carers. A sub group in the ABI caregiving literature has focused on the impact of children's brain injuries on the loss and psychosocial experiences of families, in particular on parents. Due to different role expectations for children and relationships with other family members there is recognition the results from the previous studies may not be directly comparable to experiencing a pediatric ABI survivor. The majority of knowledge derived in this area has been obtained from qualitative methods with mothers as participants. While mothers were the dominant participants demographic data on their children varied. Children's ages ranged from 1.5 -35 years. Children's' levels of brain injury varied between moderate to severe and they were between four months to 13 years post injury (Brown, Whittingham, Sofronoff, & Boyd, 2013; Fumiyo, Sumie, Akiko, 2009; Jordan & Linden, 2013; Rasor Good, 2003; Roscigno & Swanson, 2011; Wongvatunyua & Porter, 2008). Notwithstanding the variation in design and method the findings of these researchers are significant for their similarities. Overall, the responses from mothers illustrated a variety of common psychosocial experiences that collectively included: the multi-faceted and perpetual nature of the labour and burden of caring; enduring sense of loss and grieving for the child they once knew; and the need for resource building, developing family adjustment and coping strategies (Clark, Stedmon, & Margison, 2008; Conoley, & Sheridan, 1996; Fumiyo, et al., 2009; Jordan & Linden, 2013; Rasor Good, 2003; Wongvatunyu & Porter, 2008). Themes and categories established in Rasor Good (2003), Wongvatunya and Porter (2008) and Fumiyo et al., (2009) appear to suggest these psychosocial reactions can be experienced chronologically; beginning with initial reactions to the event and moving through a series of adjustment stages.

The studies by Roscigno and Swanson (2011) and Brown et al. (2013) are of particular interest as their sample sizes of 42 parents and ten parents respectively, included a small number of father participants as well as mother and father couples (interviewed separately). While the overall qualitative findings from both of these studies were largely consistent with previous research investigating the impact of pediatric ABI on mothers, two highlights are noteworthy. Experiential avoidance, the attempt to control unwanted internal experiences can lead to poorer psychosocial wellbeing and mal-adaptive coping patterns in parents (Brown, et al., 2013). Parental narratives also drew attention to how culture shapes parental sense making and psychosocial experiences in that misinformed responses and judgmental attitudes from others, including health care professionals, can have immediate and long-term psychosocial implications for parents and their child (Roscigno & Swanson, 2011). More recently, a systematic review of experiences of parenting a child with an ABI, highlighted the challenges parents face which included: parenting a changed child; adjusting to different roles; dealing with intense emotions; and social isolation (Tyerman, Eccles, & Gray, 2017).

The work of Collings (2008) is significant for the deference given to issues of grief and loss. Participants in Collings' (2008) small exploratory qualitative study were five parents (two males and three females), whose adult children were living in residential care settings as a result of an ABI sustained at the ages of 19-22 years of age and the time post injury ranged from 2.5 – 26 years (Collings, 2008). Parents reported not only did they experience acute sense of grief which eventually abated; they also experienced recurrent or re-emerging grief as it related to:

> the loss of their child as they knew them; child's inability to do normal everyday things; concern about the child's future well-being, especially in relation to appropriate accommodation; anger about the pointlessness of the situation; lack of closure relating to the fact that the object of their grief is still alive; lack of confidence in medical and/or allied health staff; lack of hope/encouragement from medical and/or allied health staff; seeing other people of a comparable age doing 'normal' things (i.e. getting married/working); impact on siblings; amount of time taken up caring for their brain injured child and consequent restriction of social interaction/activity (Collings, 2008, p.1508-1509).

Clark et al., (2008) also found mothers of much younger ABI injured children experienced an oscillating process of grief and loss. These studies demonstrated that the experience of loss, initiated by the change to the child, is not only ongoing but there are also secondary consequences of a loss involved in adapting and reorganizing life without the loved one. These two studies have added to the understanding of the relationship between loss and psychosocial factors. In summary, all of these qualitative findings have substantially added to the understanding of caregiver experiences, in particular the depth and breadth of their perceptions of loss and emotional grief responses.

Pediatric parental carer needs. Parental carer needs was the focus of a qualitative study examining parents' experiences and support needs following a childhood brain injury from the time of the accident to their child's discharge home (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2014). Findings from this study determined parents also had unmet emotional support needs across the care trajectory particularly coping with the child's behavioural and psychological difficulties and community lack of understanding the impact of the brain injury (Kirk et al., 2014).

Summary of ABI, loss and primary family member or caregiver. Female caregivers have been key informants in providing knowledge about living with ABI; suggesting that gender may be a factor for those in the carer role. Findings have consistently identified carers' awareness of loss and grief processes, impact on coping, and other corresponding negative psychosocial experiences. While continuing to highlight caregivers are significantly psychosocially compromised, findings also demonstrated that positive coping and adjustment is attainable; influenced by perceptions of mastery and being in control, specific coping strategies, supports, financial stability and positive pre and post relationships and family functioning. From carer perspectives ongoing needs of families have been identified and barriers to unmet needs are linked to service schisms.

Children and Siblings

Children. Recognition of loss experiences and psychosocial impacts on children has been under explored; however, two prominent groups of researchers have laid the foundations for knowledge development gained from listening to children. In a small pilot mixed methods study

Butera-Prinzi and Perlesz (2004) explored the post event experiences of four children (ages seven-12; three girls, one boy) living with fathers who had an ABI. Significantly, their findings highlighted the children's continued experiences of loss and grief of their former pre-brain injured fathers, alongside the losses associated with change in lifestyle, their mothers' sense of burden, threat of potential family violence and disintegration, and their own emotional distress (Butera-Prinzi & Perlesz, 2004). While the children's levels of resiliency and positive coping were noted, Butera-Prinzi and Perlesz (2004) confirmed that children living with a parent with an ABI are negatively impacted and at high risk for emotional behavioural issues.

A group of researchers in Denmark concentrating on the psychological functioning of children following a parental ABI, examined post-traumatic stress symptoms in 35 children aged seven-fourteen years (Kieffer-Kristensen & Johansen, 2013; Kieffer-Kristensen, Teasdale, & Bilenberg, 2011). Their findings from self-reported PTSD measures and parental behavioural checklists, indicated children living with a parent who has an ABI were at risk for developing post-traumatic symptoms (Kieffer-Kristensen et al., 2011). In another study, using a qualitative phenomenological approach to interview 14 children aged seven-14, researchers found the development of traumatic symptoms may have its impetus in children hiding their feelings of loss and grief in order to protect the ill parent (Kieffer-Kristensen & Johansen, 2013). Informed by the coping competence model, a review of the literature on children's' adjustments following a parental ABI concluded children are at a higher risk for depression and family violence (Tiar & Dumas, 2015). In summary, these researchers indicated children are vulnerable and at risk for mental health and behavioural concerns within a family living with ABI; and have recognized a further need for investigators to pay attention to the relational changes within the family (Butera-Prinzi & Perlesz, 2004; Kieffer-Kristensen & Johansen, 2013; Kieffer-Kristensen et al., 2011).

Siblings. The science of understanding the psychosocial influences on siblings is also in its infancy. Degeneffe and Olney (2010) analyzed 272 adult siblings (over 18 years of age) responses to a quantitatively based survey which contained five open ended questions; one question in particular asked: “How is your life different since your sibling had a TBI” (p.1416)? The participants’ responses to this question were qualitatively analyzed revealing siblings may experience major losses in their own lives such as divorce, family estrangement, and burdensome demands on their time leading to increased stress and deteriorating health (Degeneffe & Olney, 2010). As well, some participants also described experiencing more family closeness and positive life attributes (Degeneffe & Olney, 2010). The findings of Degeneffe & Olney (2010) are important for two reasons: 1) emphasized the enduring nature of the impact of ABI on loss issues over time and distance; and 2) these impacts occurred regardless of whether the adult sibling lived with or apart from the brain injured sibling.

Varying the age of the sibling population Sambuco, Brookes, Catroppa, and Lah (2012) investigated self-esteem and behavioural outcomes in the siblings of children who had sustained a brain injury. Thirty-nine siblings (eight-eighteen years of age) closest in age to the injured sibling participated by completing several measures (Sambuco et al., 2012). Outcome variable measures included; sibling behavioural outcome and self-esteem outcome while the predictor variables looked at social support and knowledge (Sambuco et al., 2012). While these researchers found no evidence of significant behavioural difficulties among siblings, they did find siblings had significant self-esteem difficulties (Sambuco et al., 2012). In summary, the limited evidence available from research with children and sibling subsystems suggests, regardless of variables of age of affected member, time since injury, and severity of injury, they also significantly experience loss and heavy psychological impacts.

Marital Relationships

Family ABI research has also explored marital relationships following an ABI. As a result of changes to the injured partner and the corresponding perceptions of loss of the couple's relationship and intimacy, an ABI event doubles the likelihood of separation and divorce (Webster et al., 1999). The literature examining post ABI marriages has focused on two concepts: marital stability and marital quality.

Marital stability. Marital stability, as a component of post injury adjustment, is often studied by examining breakdown and divorce rates of couples living with ABI (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011). According to Godwin et al. (2011), there is a wide range of marital breakdown rates located in the literature. While some findings reported high levels of marital stability rates with all levels of brain injury severity, other findings suggested there were greater separation and divorce rates amongst those with severe head injuries (Godwin et al., 2011). Recent research suggests marital breakdown for couples living with ABI is less than previous evidence has indicated, however, while relationships may remain intact, there continues to be concern directed at overall marital stability (Kreutzer, Sima, Marwitz, & Lukow, 2016). In examining factors distinguishing between stable and unstable marriages, Kreutzer et al. (2016) determined factors related to instability included lower marital quality, and shorter duration of the marital relationship prior to the ABI.

Marital quality. Marital quality is assessed using the constructs of consensus, cohesion, adjustment, satisfaction, affectional expression and sexual satisfaction (Godwin et al., 2011). Peters, Stambrook, Moore, & Esses (1990) investigated connections between brain injury and marital satisfaction, adjustment, and spousal intimacy. They focused on the marital relationship in which the male brain injured survivor had been diagnosed with either a mild, moderate or severe head injury. Both partners completed a series of self-administered questionnaires while other questionnaires were administered by the interviewer to either the spouse or ABI survivor. Peters et al. (1990) reported wives of severely injured partners disclosed overall greater marital disagreement, lower marital adjustment, and less physical or verbal affection than wives of partners with mild to moderate ABI. Peters et al. (1990) concluded predicting marital maladjustment was correlated to the brain injured partners' symptoms. Overall, findings related to marital quality primarily showed negative outcomes although two studies reported positive outcomes regarding sexual satisfaction (Godwin et al., 2011). More recently, empirical evidence suggests there is a reduction in desire and frequency of sexual intercourse in adult ABI males and their partners; coupled with survivor depression leads to lower partner harmony , decreased feelings toward each other; and problems with decision making (Bivona et al., 2016). Current research, using the conceptual framework of relationship continuity, concluded: partners who reported a range of positive relational experiences were consistently experiencing continuity (an experience of the continuation of the spousal relationship from the pre ABI state); while those who perceived discontinuity (viewing the spousal relationship as finished post ABI) viewed their partner with ABI from a medical lens (as someone who had specific deficits) were more likely to express burden and doubts about the relationship continuing (Villa & Riley, 2017).

In a current study focusing on male partner experiences of female ABI, thematic findings uncovered a fluid journey depicting the unpredictability, sorrow, frustration; and finally moving towards acceptance and commitment of their female partner (Brunsden, Kiemle, & Mullin, 2017). The men also identified limited supports, and information available for both partner and themselves during the acute stage as well as throughout the rehabilitation and recovery phrases (Brunsden et al., 2017).

In their critical review of the literature examining marriage following an ABI, Godwin et al., (2011) highlighted the majority of the data derived from only one partner’s perceptions (either the partner of the ABI survivor or the survivor themselves); thus, missing information about the whole marital relationship. Godwin et al. 2011 are strong advocates for the use of a systemic framework for research investigating dyadic relationships post ABI. In their examination of 40 survivors’ and caregivers’ authored documents (blogs, quotes and published memoirs), Godwin et al. (2014) analyzed the documents in an attempt to obtain a dyadic representation of the couple experiences following an ABI. Using grounded theory methodology two core themes emerged (Godwin,et al., 2014). The first theme focused on the impact of the ABI on the couple with couples identifying four types of ambiguous loss: you me and us; security; connectivity; and loss of the future (Godwin et al., 2014). The second theme concentrated on the process of redefining and rebuilding the sense of self as a couple, highlighting; a shared intentional purpose; regenerating connection; developing a tolerance for the ambiguity; and refining of commitment (Godwin et al., 2014). From these findings a relational theory was developed to understand the “totality” of the change in the couples’ relationship (Godwin et al., 2014). The concept of totality denotes the holistic process of the overlay between individual experiences (Godwin et al., 2014).

Although the method of data gathering used by Godwin et al., (2014) did not involve joint couple interactions, this recent research is noteworthy for its contribution towards understanding inter-partner dynamics. In summary, research with the marital subsystem indicates couples experience numerous losses related to the ‘us’ in couple that can ultimately lead to marital dissatisfaction and dissolution.

Family system

While there is growing interest in the experiences of the family as a whole, to date, only a limited number of studies have explored this area. In a study to identify predictors of family system functioning Gan et al. (2006) used archival records as a data source, and quantitatively analysed questionnaire responses from family informants within the same household. They found families with an ABI member showed more distressed family system functioning compared to a normative sample (Gan, et al., , 2006). These findings are salient as they support the theory that entire families and not just individual family members experience the impact of ABI. Landau and Hissett (2008) employed the family group as a unit of analysis to explore the relationship between loss of identity issues faced by the family member with a mild brain injury and the family's sense of loss of the member who is now different. Three interviews were conducted: one with only the brain injured person; one with family members without the brain injured person and one with both the brain injured person and the other family participants (Landau & Hissett, 2008). Their results indicated as the mild brain injured person increasingly experienced identity ambiguity the family experienced increasing loss of the injured person as well as loss of the family system as it was prior to the ABI; thusly affecting present and future identities of the entire family (Landau & Hissett, 2008).

Using data from family group interviews (12 adults, 12 children of various ages), to investigate families' experiences with critical illness in an intensive care setting, Kean (2010) determined of the initial psychosocial experiences it was only the families with a member suffering from some degree of ABI that experienced ambiguous loss. Ambiguous loss was noted in families' perspectives surrounding the psychosocial impact on their families' futures in that even the idea of a future was elusive (Kean, 2010).

To obtain family perspectives of psychosocial transitions during the first 18 months post moderate –severe ABI, Whiffin, Bailey, Ellis-Hill, Jarrett and Hutchinson (2015) employed a qualitative narrative design. Nine non injured family members from three families were interviewed separately at one, three, and 12 months post ABI and the data was analyzed on three levels: the individual, the family, and between family units (Whiffin, et al., 2015). Analysis revealed interrelated narratives demarked by struggling with accumulated loss and psychosocial change (Whiffin et al., 2015). To determine the dynamics of relationships in families of patients with brain injury, using relational level data collection, separate individual interviews with the spouse and a family of origin member (i.e. father, mother, sibling or child) were completed (Segev, et al., 2018). In the 10 family cases studied it was the male of each family that had incurred the ABI (Segev, et. al., 2018). Their findings revealed, while the brain injury had changed the relationships in all the families included in the study; the impact of these changes effected families differently; identifying two types of families 'complex and embracing' (Segev, et. al., 2018). The 'embracing families' appearing to enjoy less functional difficulties in family relations were able to use their relationships as a resource for each other and developed meaning of the ABI situation which helped their ability to cope (Segev, et. al., 2018).

Although limited in number these studies are important because they highlight families as a system and provide new information about the interrelatedness of loss and psychosocial issues between family members.

Summary of ABI, loss and the family system. An examination of the literature clearly revealed loss and reactions to loss are formidable experiences for individual family members living with ABI. The evidence has consistently established experiences of loss originate from the neurobiological sequelae following an ABI event, and the hidden nature of these neurological residual effects is what differentiates these loss experiences from other chronic illnesses. The described impact of ABI on individual family members has included perceptions of the loss of themselves and the loss of the person they once knew. The ensuing reactions of increased stress, strain and caring obligations; diminished quality of life; life satisfaction and well-being have been substantiated in the literature. While current evidence denotes a holistic shift in family treatment and care planning, family system research continues to lag behind.

Empirical Evidence of Family Research

Critical analysis of the literature has revealed the majority of scholarship, obtained from quantitative and qualitative studies, has derived from *family-related* research and not *family* research. Therefore, the limitations in the literature are centered on methodology.

Use of a conceptual framework. In acquiring this knowledge about the impact of ABI on families, the first limitation noted in the literature was the limited use of a theoretical foundation or conceptual model. In conducting family research, in order to ensure consistency with the study design, it is important to use a theory or concept underpinned by a systems framework (Marcellus, 2006). Two prevailing forms of systems theory within applied health research are the human ecological theory and family systems theory. Human ecological theory proposes humans are in interdependent relationships with their environment (Bubolz, & Sontag, 1993). Family systems theory is based on the premise family members are in a continuous circular cycle of interaction where each person is responding to their perception of the other, thus placing the emphasis on family as an entire entity greater than the sum of their individual parts (Smith, & Hamon, 2012). The need for research studies to incorporate family systems in understanding the impact of ABI on families has been advocated by Brooks (1991), Perlesz et al. (1999), Minnes et al. (2000), Degeneffe, (2001), Wongvatunyu & Porter (2008), Fumiyo, Sumie, Akiko, Yasuko (2009);

Roscigno & Swanson (2011), and Godwin et al. (2011); yet a heavy preponderance of ABI family research continues to lack a family systems framework. Paradoxically, within the ABI literature there is increased application of family systems theory in family intervention strategies. To promote the use of family systems theory in treatment, articles have been written by Kreutzer et al. (2010) and Stejskal, (2012) for the purpose of educating professionals who provide care for those affected by ABI on the family systems paradigm. Research on family therapy interventions have focused on: the effectiveness of family therapy (Butera-Prinzi, Charles, & Story, 2014; Laroi, 2003; Perlesz, & O'Loughlan, 1998); building engagement with families throughout the rehabilitation journey (Moore Sohlberg, McLaughlin, Todis, Larsen, & Glang, 2001); a network of community family services (Tyerman & Booth, 2001); and the development of family intervention programs (Gan & Ballantyne, 2016; Gan et al., 2010; Gauvin-Lepage, Lefebvre, & Malo, 2015;Kreutzer, Stejskal, Godwin, Powell, & Arango-Lasprilla, 2010).

However, there has been a turn in recent literature shifting away from family system involvement as the primary goal of treatment towards viewing family as the framework from which care can be provided; thereby advocating for a family-centered care model that encourages relationships and collaborations between health carers, individuals and families (Creasy, Lutz, Young, & Stacciarini, 2015).

As evidenced previously (Gan, et al., 2006; Godwin et al., 2014; Kean, 2010; Landau & Hissett, 2008; Whiffin et al., 2014), when research with families is informed by congruence with a systems perspective new knowledge is acquired about the whole of families' experiences living with ABI. By addressing this limitation this study will continue to build knowledge that can be useful for informing family centered practice. As outlined in chapter one, ambiguous loss theory crafted to capture families' experiences with a particular stressor event, underpinned this study.

The theory of ambiguous loss has been utilized for both clinical and research purposes. Boss and Couden (2002) presented a case study illustrating the theory of ambiguous loss as applied to therapeutic interventions with a family experiencing a chronic physical illness. Betz and Thorngren (2006) defined and characterized types of ambiguous loss and developed a counseling model for use with families encountering ambiguous loss events. Ambiguous loss theory was the basis for family-systems interventions in treating polytrauma military patients and their families (Collins & Kennedy, 2008). The framework of ambiguous loss theory was used to guide a process for further understanding gender transitions in families (McGuire, Catalpa, Lacey, &Kuvalanka, 2016), the meaning of family for children in foster care (Mitchell, 2016), and voluntary separation in transnational families (Solheim & Ballard, 2016). The cross- cultural applicability of ambiguous loss theory is noted in studies examining the families of the disappeared in post conflict Nepal (Robins, 2010); understanding complicated grief of parents of the disappeared in northern Uganda (Hollander, 2016); and understanding lifelong ambiguous loss of Cuban exiles (Perez, 2016). The authors of these studies focused on the type of ambiguous loss when a loved one is physically absent yet kept psychologically present and in so doing have demonstrated that the process of complicated loss and grief crosses ethnically diverse populations.

Numerous qualitative studies, from a broad spectrum of humanistic fields, have explored a range of situations and experiences framed by ambiguous loss theory: post divorce families (Affi & Keith, 2004); same-gender (lesbian) divorce with children (Allen, 2007); couples coping with mild cognitive impairment (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007); adult family members caring for a member with dementia (Dupuis, 2002); caregiving wives of veterans with dementia (Ford, Linde, Gigliotti, & Kim, 2012); seventh-day Adventist women in mixed-orientation marriages (Hernandez & Wilson, 2007); parental deployment and youth in military families (Huebner, Mancini, Wilcox, Grass, & Grass, 2007); mild traumatic brain injury (Landau & Hissett, 2008); families of brain injured ICU patients (Kean, 2010); foster children (Lee & Whiting, 2007; Samuels, 2009); HIV/AIDS (Mosack, Abbott, Singer, Weeks, & Rohena, 2005); families with a member who is trans-identified (Norwood, 2013); families of children and autism spectrum disorder (O' Brien, 2007); and families with children with severe or profound disabilities and out of home care (Roper & Jackson, 2007).

According to Carroll et al., (2007), the specific construct of boundary ambiguity has been widely used in family stress research. Carroll et al., (2007) identified 37 published articles that used boundary ambiguity as a primary conceptual variable. In particular, several research projects set out to operationalize and measure and validate the construct; resulting in the development of and revisions to the Boundary Ambiguity Scale (Carroll et al., 2007). Of note Carroll et al. (2007) observed that many scholarly researchers tended to interpret the term 'ambiguous' as the subjective and emotional responses of individuals and family members rather than its original intended definition as the objective stressor event or situation.

Critics of ambiguous loss theory acknowledge the nonpathological approach to a unique loss process in removing the blame and shame of a problem attached to an individual is a strength (McGuire et al., 2016). A limitation that has been expressed is the lack of generalizability of findings to other contexts, in particular to perceptions of other family members (Afifi & Keith, 2004). However, as much of the research on ambiguous loss theory has been *family-related* research, this limitation maybe open for review in the context of *family* research.

So how do families' experiences living with an ABI look through the lens of ambiguous loss theory? Individuals affected by an ABI can experience a range of cognitive, behavioural and emotional impairments that may cause significant disruptions and or changes to their psychosocial presence and identity. These alterations are often not visible, rather hidden from the view of the affected individual as well as their family members. The individual with the ABI is ‘seen’ to be in ‘body’ the same and yet at the same time acting and being a ‘different person’ – there but not there; thereby creating an ambiguous loss event for all family members. This particular ambiguous loss situation can create significant stress and trauma, burden, boundary ambiguity and experiences of loss as families and their loved ones struggle to cope, adapt and function.

Within health science disciplines the theory of ambiguous loss has received limited recognition and utilization. The theory of ambiguous loss provided an alternate perspective from which to view the impact of ABI on families. Individuals’ and families’ perceptions of and responses to their loss are legitimized allowing for their reactions and functioning to be viewed as an acceptable expression of their experiences rather than pathologized, labelled and or seen as something to be ‘fixed’. In this systemic context, ambiguous loss theory allowed for exploration of families as ‘whole’ units of analysis in which experiences, reactions, beliefs and attitudes can be considered as a product of the system rather than the sums of the separate components. The knowledge gained by studying families’ experience living with ABI through the lens of ambiguous loss theory, can contribute to understanding family experiences and inform family centered practice.

Family as unit of analysis. A secondary connected limitation in this literature is the lack of congruence to family as an integrated unit, in data collection and analysis strategies. Other researchers in the field of family nursing and the discipline of psychology have been employing family as unit of analysis and transactional level data strategies to examine families experiencing health and health related issues: hospitalization of children (Bousso & Angelo, 2003); critically ill adults (Eggenberger & Nelms, 2007); death and grief (Thirsk & Moules, 2013); and negotiating rehabilitation after stroke (Medved, 2011).

The unit of analysis for this study included both the individual family member and the family. This integrated perspective eliminated the decision to research either the individual or the family by placing both the individual as family member and family in the foreground. This allowed for both the individual and family system to be studied together (Robinson, 1995) generating transactional level data amongst multiple family members (Fisher et al, 1985; Sullivan & Fawcett, 1991).

Beyond nuclear family. Thirdly, the literature denotes a reliance on a definition of family that is limited only to the nuclear family. This investigation used a broader holistic definition of family, ‘family is who they say they are’, fitting with current conceptual and social trends (Wright, & Leahey, 2009). The concept that the family is who they believe themselves to be, while vague, allows families to consider membership based on ‘caring’ and ‘relational’ attributes that can extend to children, siblings, extended biological and legal members as well as close friends who are integral in providing support to the family.

To conclude, this critical analysis of the literature has emphasized the significance of loss experiences for survivors and individual family members and identified the limitations in methodology which this study addressed. To investigate families’ perspectives of the impact of an ABI event and explore how families make sense of their experiences living with ABI, have been made more salient through the foundations laid by this literature appraisal.

Chapter Three: Methodology and Research Methods

Methodology, according to Crotty (1998) is the master research blueprint or strategy that justifies the choice and use of particular methods to align with the research question, and in designing family research it is important to ensure study integrity with congruence to the theoretical underpinnings, data collection, and measures of analysis (Marcellus, 2006). In this chapter, the methodological characteristics of narrative inquiry are outlined and justification given for the chosen model of narrative inquiry by Lieblich, Tuval-Mashiach, &Zilber, 1998; followed by a detailed description of the research methods and decisions employed in conducting this study. Discussion of trustworthiness and ethics conclude this chapter. However, to begin it is necessary to define the language of narrative.

Defining Narrative

Humankind, from time immemorial, has embraced narratives. Indeed, there are those who claim that narratives are central to human life. Sandelowski (1991) in capturing the purpose of narrative for human beings summarized:

> Narration, therefore, constitutes a kind of: a) causal thinking, in that stories are efforts to explore questions of human agency and explain lives; b) historical (as opposed to scientific) understanding that events cannot be explained except in retrospect; c) moral enterprise, in that stories are used to justify and serve as models for lives; and a kind of d) political undertaking; in that individuals often struggle to create new narratives to protest a perceived storylessness in the old ones. (p. 163)

In this current age of the widespread use of the World Wide Web and social networking, the narrative term has been bandied about and associated with many things. However, while narratives are everywhere not everything is a narrative (Riessman, 2008). For the purpose of valid research, scholars require a clearer boundary in determining what constitutes a narrative. There are challenges to defining narrative as it can hold multiple meanings and be utilized in a variety of ways by different disciplines (Bold, 2012: Riessman, 2008). As well, “narrative” and “story” are often applied synonymously (Riessman, 2008) although other scholars characterize them as distinct terms (Smith & Sparkes, 2009). Nonetheless, scholars have achieved a general consensus to the components that form narrative. Narratives are a connection of events that contain a point; revolve around specific characters; and, have a plot that unfolds sequentially over time and space (a place or situation) (Clandinin & Connelly, 2000; Elliot, 2012; Riessman, 2008; Smith & Sparkes, 2009).

The power of narratives lies in the storytelling, not necessarily as it is lived but as it is ‘told’. The power of storytelling is a distinguishing feature as narratives are told to others to convey meaning and in so doing appeal for the audiences’ attentions and judgements (Brannen, 2013). In this regard narratives are also considered to be performative (Riessman, 2008). Narratives can be defined as communications of human experiences told through a sequential order that relate events in a meaningful way for a particular audience (Elliot, 2012). While researchers often use the term narrative when referring to its general dimensions and properties, people tell stories: “the process of storytelling is something they *do* or perform to transmit a message” (Smith & Sparkes, 2009, p. 2). For this research study the terms narrative and story will be used to denote this subtle distinction. Narrative inquiry is the study of peoples` stories.

Narrative Inquiry: Philosophical and Methodological Foundations

In order to maintain study integrity an epistemological paradigm must underpin the theoretical framework, research methodology and methods, (Marcellus, 2006). The consequence for research that is not epistemologically consistent is that its ability to be applied to practice can be compromised (Marcellus, 2006). Narrative inquiry is embedded in the epistemological position of constructionism. Constructionism supposes that meanings are co-constructed, subjective and interpreted into multiple realities (Crotty, 1998). Historically the epistemology of constructionism arose from a rejection of the objectivist view of the nature of reality (Crotty, 1998). The objectivist view stated reality and knowing what is real, resides outside of human consciousness, therefore meaning is posited and discovered (Crotty, 1998). Constructionism espouses there are multiple realities and meanings that come out of a reciprocal engagement process between humans and their world (Crotty, 1998); therefore “meaning is not discovered, but constructed” (Crotty, 1998, p. 9). According to Crotty (1998), constructionism also positions itself firmly within a social perspective, referring to an already pre-existing social system of meaning. Humans are born into a social system of meaning – culture. Humans are members of social groups and culture provides humans with pre-set meanings of not only social constructs like behaviour and emotions but also of natural and physical constructs (Crotty, 1998). Co-constructed meanings infer there is no absolute truth rather a multiplicity of subjective truths or perceptions (Boss, 2006; Lieblich, Tuval-Mashiach, &Zilber, 1998). A major tenet of constructionism states there are no true or valid interpretations just useful interpretations (Crotty, 1998; Lieblich et al., 1998).

These epistemological assumptions connote individuals construct stories out of cultural life as a method of telling about their lives and assembling meaning (Polkinghorne, 1988). Ontologically, narrative is perceived as a condition of social life, therefore, to be human is to be storied (Smith & Sparkes, 2009). Narratives are regarded as the preeminent way in which humans form meanings (Maloney, 2008; Polkinghorne, 1988; Riley & Hawe, 2005). The purpose of narrative inquiry is to capture how people make sense of their world and to reveal the meanings represented in the narratives. Therefore, narrative inquiry mirrors the ways in which human beings interpret their world (Sandelowski, 1991).

Narrative inquiry shares similar characteristics with other forms of qualitative research methodologies in examining meanings, interpretations, and subjective experiences of family members. However, in narrative inquiry context takes a foreground position (Riessman, 2008). There are contextual characteristics in narrative inquiry that are distinguishable, making it an effective methodology to reveal how families make sense of living with ABI. In the next section, several of these characteristics will be examined to support the use of narrative inquiry with families' experiences living with ABI.

The Use of Narrative Inquiry with Families' Experiences Living with ABI

Narrative inquiry has potential relevance for applied health science family research, in particular, examining lives impacted by chronic illness. The distinguishing characteristics of meaning, relatedness, identity and temporality are applicable for examining families' experiences living with an ABI.

Narrative and Meaning

As stated previously, an essential quality of human existence is to give meaning to life through the active involvement of interpreting experiences; thus, narrative inquiry allows for meanings to be considered as a basis of people's actions (Smith & Sparkes, 2009). The borders of narratives move beyond the individual to families as families build narratives (Fiese & Sameroff, 1999). Family systems theory recognizes while people are individuals, they are also a part of a family system and that a person's feelings and behaviours are intertwined with and influenced by others in the system (Maitz, 1991). Similarly, as narrative inquiry not only reveals the ways in which individuals interpret their world, it can also unveil the ways families interpret their world. Family narratives are built from reflecting on how they make sense of their world, express rules of interaction and create beliefs about relationships (Fiese & Sameroff, 1999). In recounting events, families often co-construct a set of perspectives that personify their struggles (Fiese, & Spagnola, 2005). Meaning making in the family is associated with family adaptations to stressful conditions such as: immigration (Farias & Asaba, 2013); mental illness (Stern, Doolan, Staples, Szmukler, & Eisler, 1999); acquired brain injury (Boss, 2006; Hyden & Antelius 2011; Medved, 2011); infertility (Sandelowski, Holditch-Davis, & Harris, 1990); and, organic brain issues (Hyden & Orulv, 2009; Hyden, 2011). One outcome of co-constructed meanings is evident in the beliefs and values that families form (Wright &Leahey, 2009). Families' belief and value systems form the basis for patterns of behaviour and emotional experiences of family members. Therefore, families' abilities to adapt to stressful and chronic health events like an ABI are shaped by their beliefs (Boss, 2006; Wright & Leahey, 2009). By illuminating meaning, narrative inquiry focuses on *understanding* the families' beliefs and values that underpin their thoughts, feelings and actions. Therefore, narrative inquiry provides the opportunity to facilitate examination of the implicit, explicit, differing, and unexamined beliefs that families hold about relationships and critical events (Fiese & Spagnola, 2005).

Meaning making functions are, however, common in other qualitative approaches such as phenomenology, grounded theory and, ethnography (Gilgun, 2005). With narrative inquiry, meaning is privileged as narratives are also recognized as being embodied (Smith & Sparkes, 2009). People depend on their bodies to engage with the world. They, therefore, tell stories through their bodies as the body projects subjective realities (Smith & Sparkes, 2009. Family members use their bodies to communicate and relate with each other. Individuals and families affected by ABI will also use their bodies in telling their story to others. The ability of narrative inquiry to capture embodied meanings is an important feature.

Meaning evokes empathy (Elliot, 2012). Empathy is acknowledged to be a powerful component in addressing health care providers' abilities to connect and develop therapeutic relationships with their clients (Martin, 2011). The outcome of a study that evaluated the use of client narratives to reduce stigma in health care professionals suggests the empathy levels of psychiatric nurses increased (Knaak, Szeto, Robinson, Karpa, & Patten, 2013). The increased empathy in nurses was linked to their ability to identify with the individual participants' meanings of being human rather than being just their mental illness (Knaak et al., 2013). This study suggests findings from a narrative inquiry research approach have the potential to expand the empathetic capacities of health professionals supporting individuals and families living with ABI; furthering the development of family centered care.

Narrative and Relatedness

Narrative inquiry is distinguished from other qualitative methodologies in terms of the position it affords relatedness, as it encourages a focus on the ways relationships between people shape, enable and restrict lives (Smith & Sparkes, 2009). For families, relatedness is associated with the bonding of its members leading to a sense of belonging (Broderick, 1993). Bonding and attachment are reciprocal processes leading to ties of affection (Wright & Leahey, 2009). Families' sense of belonging is governed through rules families develop to maintain family boundaries (Broderick, 1993). For families experiencing an ABI event, relationships between family members are significantly altered causing disruptions to families' capacity to maintain boundaries and affectionate ties around who still belongs (Boss, 2006, Kean, 2010; Landau & Hissett, 2008). The work of Hyden & Antelius (2010) with couples, in which one spouse has a communication disorder, is an example of using narrative inquiry to explore issues of relatedness. By concentrating on the communicative forms individuals with communication disorders use in order to negotiate the telling of a story or be a part of a story, Hyden & Antelius (2010) demonstrate the importance of jointly constructed stories contributing to maintaining a sense of coupleness. The use of narrative inquiry with families affected by ABI, will allow for the inclusion of multiple voices providing a fuller exploration of the relationship dynamics between family members.

Narrative and Identity

Stories are vital to the development of individuals (Mishler, 1995) and families (Broderick 1993, Boss, 2006) as they provide a structure through which identities are formulated (Lieblich et al., 1998; McMahon & Watson, 2013). In other words, as stated by Lieblich et al. (1998), “narratives provide us with access to people’s identity and personality” (p. 7). Identities are shaped along two pathways: 1) the stories individuals create about themselves as they experience themselves in relation to others; and, 2) the stories others tell about their perceptions of the individual (Corey, 2009; Lieblich et al., 1998; Mishler, 1995). Identities can change through the re-telling of experiences told at different points in people’s lives (Mishler, 1995), so as stories change so do identities (Corey, 2009). Iteratively, as identities alter so do the stories. Boss (2006) explained through families’ patterns of interacting, families develop a family identity. According to Boss (2006), the connections families develop with their social world mold their perceptions and identities, and as families’ relationships with internal members and external systems are revised so are their family’ identities. An ABI event has the capability of destabilizing and disrupting families’ identities through role confusion, and changing family patterns of functioning and behaving (Andreatta, 2008; Boss, 2006; Kean, 2010; Landau & Hissett, 2008). Boss (2006) contends that intervention strategies need to include a process of assisting families in restructuring their identities. The use of narrative inquiry with families affected by ABI would help the researcher comprehensively examine identity issues. Given the psychological focus on families' perceptions on experiencing ABI, Burck (2005) states: "narrative analysis helps the researcher to examine issues of self-presentation in an overall way, which grounded theory and discourse analysis miss through their focus at a different level" (p. 256).

Narrative and Temporality

Temporality, the notion of time, is a key construct in narrative inquiry (Clandinin & Connelly, 2000). The definition of temporality as affixed to narratives denotes that life is not only experienced in the 'here and now'; experiences also have a past, and a potential future (Clandinin & Connelly, 2000). Stories are situated within historical contexts (Clandinin & Connelly, 2000) and enable a "looking back and recounting lives" (Riessman, 2008, p. 7). Some scholars claim time is an ontological construct as, "Experiences do not simply appear to be connected through time; they are continuous" (Clandinin & Rosiek, 2007, p, 40). The very nature of ABI is temporal, as families' experiences encompass time prior to the brain injury event and includes time post injury. The fluidity of time was demonstrated in a study examining a family's meaning making processes of "recovering" and "recovered" following the mother's brain injury (Medved, 2011). In the analysis of the family's conversations surrounding a particular event, Medved (2011) established how "recovering" meant the present time, while "recovered" was considered for time in the future.

The notion of temporality is also situated in the phenomenological state of lived experience (van Manen, 1990). In narrative inquiry temporality is the primary method of organizing experiences and documenting the passage of time (Smith & Sparkes, 2009). Families' use of language, tenses (i.e. before, now, and after) can create storytelling that involves a beginning, middle and an end (Smith & Sparkes, 2009). The use of narrative inquiry with families impacted by ABI would allow for a more thorough investigation of families' overall experiences through time, in particular time before the ABI event and time after the event. In summary, the integration of these distinct characteristics of narrative inquiry will inform the research process in helping to address the question: how do families make sense of their experiences living with ABI? As confirmed by Lieblich et al. (1998): "The entire evaluation of a real-life problem [i.e. ABI] may be tackled by a narrative approach" (p. 3).

Narrative Inquiry: Models of Analysis

As previously noted, narratives include multiple elements. Methods of narrative analysis need to consider the various strategies in which the parts of narratives can be analyzed. There is no one correct narrative analysis method and scholars agree that the choice of the method of analysis needs to be consistent in fitting with the research question, unit of analysis, and theoretical frameworks (Clandinin & Connelly, 2000; Lieblich et al., 1998, Marcellus, 2006; Riessman, 2008). Families are complex and the central tension in examining families narratively is that no family, no matter what the event, has absolute shared meanings. The facilitation of family narratives occurs during a joint interview process that involves multiple family members. In the interviews, it is critical the researcher elicits diverse views from individual family members as it is through the range of similarities, and differences that family narratives are constructed. In choosing a model of analysis for family narratives it is important the methods of analysis allow for the deconstruction of the individual perspectives and the re-construction of the overlay between individual experiences. The final interpretive product becomes the greater family narrative.

Qualitative researchers can choose from a variety of models of narrative analyses. Polkinghorne (1988), Mishler, (1995), Fiese &Sameroff (1999), Webster & Mertova (2007), Clandinin & Connelly (2000), Riessman (2008), and Lieblich, Tuval-Mashiach & Zilber (1998) have all developed models of narrative analysis. In relation to narrative inquiry with families' experiences with an ABI event, three models were chosen for further examination: Lieblich, Tuval-Mashiach & Zilber (1998), Riessman (2008) and, Clandinin & Connelly (2000). The proceeding sections describe and critique these models and outline the justification for determining the model developed by Lieblich et al., (1998) was deemed most suitable for the study.

Model of Narrative Analysis by Lieblich, Tuval-Mashiach, & Zilber

This particular model of narrative analysis is rooted in the context of life-story research. In life-story research the narrative is the active telling of a life-story. Life-stories are holistic retrospective accounts of memories of past events, situations, actions, and relationships (Brannen, 2013). Lieblich et al.'s (1998) research on life-stories is particularly embedded within the discipline of psychology and is based on the psychological assertion that life stories are linked to and become people's identities. In procuring a life-story narrative, Lieblich et al. (1998) use a stage outline procedure. Interviewees are asked to think about their life as a book and to insert their life into titled chapters that are structured around age. To further demonstrate this procedure Lieblich et al. (1998) provide an example of 'Sara's' stage outline:

Stage 1: From birth to 6, - titled Childhood
Stage 2: 6-12/13, - titled Elementary school
Stage 3: 13-18, - titled High school
Stage 4: 18-20 – titled Army
Stage 5: 20-30 - titled The work of teaching as a single woman
Stage 6: 30-40 – Building a family (p. 30)

Once the stage outline is completed, the researcher/interviewer focuses the narrator (interviewee) on four questions for each stage: 1) "Tell me about a significant episode or a memory that you remember from this stage; 2) What kind of person were you during this stage?; 3) Who were significant people for you during this stage, and why?; and 4) What is your reason for choosing to terminate this stage when you did?" (Lieblich et al., 1998, p. 26).

Lieblich et al. (1998) organized and classified their approaches to analysis of narratives along two major dimensions which they labelled: A) holistic versus categorical; and B) content versus form. 'Holistic' in Dimension A refers to the unit of analysis, whether the text is analyzed as a 'whole' or in subsections (Lieblich et al., 1998). 'Categorical' in Dimension A is similar to traditional content analysis in which individual lines in the text are analyzed and select words and or phrases are then organized into categories (Lieblich et al., 1998). Dimension B is concerned with distinctions between content and form of text (Lieblich et al., 1998). Content analysis prioritizes either the explicit or implicit content of a narrative account, while form analysis is focused on: plot structure; event sequencing; elements of temporality; levels of coherence; invocation of feelings; and, style of the narrative (Lieblich et al., 1998). Intersecting dimensions A and B results in a grid of four cells: "holistic-content; holistic-form; categorical-content; and categorical-form" (Lieblich et al., 1998, p. 13). According to Lieblich et al. (1998) narrative material can be analyzed using only an individual cell or in combination with other cells. Although Lieblich et al's. (1998) area of narrative research is centred on the form of life-stories they acknowledge their classifications of analysis are useful for other narrative forms.

Model of Narrative Analysis by Riessman

Riessman (2008) developed a generalized systematic method of narrative analysis incorporating sociolinguist, ethnomethodological and phenomenological techniques. Riessman (2008) presents four analysis approaches: thematic narrative analysis; structural forms of analysis; dialogic/performance analysis; and, visual analysis. According to Riessman (2008), these four methods can accommodate different kinds of research questions, epistemological and theoretical frames, and, units of analysis (individuals and or groups). Riessman's (2008) approaches are not situated within an overall specific procedure rather she outlines the distinct analysis techniques of each approach. Riessman (2008) locates her model of analysis in narratives of personal experience; however, the interpretations refer to the broader socio-cultural contexts of meaning. Thematic narrative analysis is exclusively focused on what is being said, the content of the narrative (Riessman, 2008). The attention in structural analysis is on the form of the telling of the narrative, emphasizing how the narrative is being told (Riessman, 2008). In describing the structural analysis approach Riessman (2008) relies heavily on the work of social linguists William Labov and Joshua Waletzky. Riessman (2008) calls the dialogic/performance approach a hybrid of methods informed by discourse analysis as the focus is on the reciprocal interactions between participants and the interviewer or a participant and the interviewer. This approach is an attempt to capture the contexts in which narratives are being produced. "Simply put …the dialogic/performative approach asks 'who' an utterance may be directed to, 'when', and 'why', that is for what purposes?" (Riessman, 2008, p. 105). The category of visual analysis is a combination of the other three approaches to analyzing visual images. Riessman (2008) explicitly states her four approaches to narrative analysis "are not mutually exclusive…they can be adapted and combined" (p. 18).

Model of Narrative Analysis by Clandinin & Connelly

Clandinin & Connelly's (2000) focus is on a model of narrative analysis that generates a narrative as the final product. Clandinin & Connelly (2000, 2010) use a narrative style to describe the processes involved in creating narratives, paying particular attention to negotiating the three-dimensional spaces (temporality, social and personal, and place) created from the relational tensions that live between people, events, and things. Underpinning Clandinin & Connelly's model are the ideas of John Dewey “who believed that examining experience is the key to education” (Clandinin & Connelly, 2000, p. xiii). Through focusing on self-reflective practices Clandinin and Connelly’s (2000) model examines the ways in which teachers’ narratives shape and inform their practice (Bell, 2002). As a result, Clandinin & Connelly’s model is used almost exclusively within educational research. An example of this approach is evident in Li, Mitton-Kukner & Yeom’s (2008) presentation of three teacher narratives describing their cross-cultural personal experiences in learning to teach.

Critical Analysis of the Narrative Models

These three models are distinctive from other qualitative methods of analysis in that they share a case-centered commitment. In other words, stories are kept intact by preserving sequences in each case (particular person, group, or situation over a period of time) instead of dividing up components across cases (Riessman, 2008). Of the three models Clandinin and Connelly (2000) is most dissimilar. First, their model produces a different outcome. Clandinin and Connelly’s (2000) model is representative of a narrative analysis for which the purpose is to gather descriptions of events and happenings and then produce a final interpretive narrative (Polkinghorne, 1998). The models of Lieblich et al. (1998) and Riessman (2008) are characterized as analysis of narratives using stories as data and then applying different methods of analysis to produce an interpretation of the data (Polkinghorne, 1998). The intended data collection strategy of examining families’ experiences living with ABI is to gather narratives. Second, and most important, is the status of the position of the researcher within the narrative analysis process. In Clandinin and Connelly (2000) the researcher’s experience is placed prominently in the foreground. The intent of examining families living with ABI is to explore the families’ experiences with this phenomenon NOT the researcher’s reflections on their own familial experience with a member who has an ABI. For some scholars, Clandinin and Connelly's model can be viewed as a form of autoethnography; the use of self to explore broader sociocultural issues (Foster, McAllister & O'Brien, 2006). A major criticism of autoethnography is its excessive use of subjectivity that is seen to limit the overall credibility of the research methodology (Foster, et al., 2006). Third, Clandinin and Connelly's (2000) exemplars singularly focus on the building of narratives from individual cases, implicitly giving the message that their model may not be able to accommodate multiple family members as the unit of analysis. For the three reasons outlined, the model proposed by Clandinin and Connelly (2000) was deemed to not be the best fit with the other methodological elements underpinning the intended family ABI study. Therefore, it was not chosen as the preferred method of narrative analysis.

The models of Lieblich et al. (1998) and Riessman (2008) are similar in that they both provide organized definitive structures for analysis of narratives (helpful to novice narrative researchers), that can be used in different contexts. However, Riessman's (2008) typology is more comprehensive as it offers a greater variety of analysis approaches. Riessman (2008) explicitly states and provides examples of her analysis methods for use with either individual or group units of analysis. Although the narrative analysis model of Lieblich et al. (1998) is derived from individual life stories, Lieblich acknowledges their model can be used in relation to joint texts from several family members, and to do so will be rather original (A. Lieblich, personal communication, January 27, 2014). In relation to narrative inquiry with families' experiences with an ABI event, Riessman's (2008) model of narrative analysis is a fit and could have been adopted as the model of analysis for this study. Although the model of Lieblich et al. was the primary approach used in this study, ultimately Riessman's (2008) approach was used to guide the thematic analysis across all families.

Model Justification

The narrative inquiry model of Lieblich et al., (1998) was chosen as the primary analysis approach, firstly, because their model is characterized as using stories as data and then applying different methods of analysis to produce an interpretation of the data. The data collection strategy of examining families' experiences living with ABI is to gather narratives. Secondly, is the status of the position of the researcher within the narrative analysis process. In Lieblich et al's. (1998) model the researcher's experience is placed in the background not foreground. The intent of examining families living with ABI was to explore the families' experiences with this phenomenon NOT the researcher's reflections on their own familial experience with a member who has an ABI.

Thirdly, although the narrative analysis model of Lieblich et al. (1998) is derived from individual life stories, Lieblich acknowledges their model can be used in relation to joint texts from several family members, and to do so will be rather original (A. Lieblich, personal communication, January 27, 2014). Fourthly, Lieblich et al's (1998) use of the stage outline procedure can be used to help families structure their narratives to develop chapters based on their lives pre-ABI and post ABI. Once these chapters are established questions can be directed at each stage. For example: 1) Tell me about a significant episode or memory before the brain injury that was very good, very bad, or non-typical; 2) Tell me about a significant episode or memory that was very good, very bad or non-typical following the brain injury; and 3) What kind of family were you during this stage? An advantage of this stage outline and accompanying question/directions lies in its ability to promote the sensitive development of different versions and a deeper understanding of families' experiences. Fifthly, the two holistic classification cells from Lieblich et al's (1998) model analysis are consistent with the theoretical principles from systems perspectives in which the sum of the whole is greater than the sum of individual parts. The implication is that similarities and differences of individuals in the family group can be clearly identified, and incorporated into whole patterns and themes, thereby capturing the family as a unit since no single family member can recount the experiences of the impact of ABI for the whole family. Another theoretical link is that Lieblich et al. (1998) and Boss (2006) share the same assertion regarding the importance of identity to narratives. The psychological focus on identity in life-stories Lieblich et al. (1998) is also seen in Boss's (2006) premise that an ambiguous loss situation, like an ABI event, can significantly affect families' identities. The ability for a model of analysis to highlight identity issues for family members affected by an ABI situation has implications for informing the therapeutic practices of health care professionals.

Research Methods

Research methods are the building blocks of strategies and procedures used to gather and analyze data (Crotty, 1998; Polit, & Beck, 2012). The research methods outlined in the following sections were in keeping with the research question, 'how do families make sense of their experiences living with ABI?'; the philosophical position (constructionism); the theoretical framework (ambiguous loss); and the methodological approach (narrative inquiry).

Sample and Participants

Researchers use purposive sampling to select members of a population who are judged to be knowledgeable of a particular phenomenon (Polit & Beck, 2012). The power of purposive sampling is the ability to select information rich cases for in-depth study (Sandelowski, 1995). For this qualitative narrative inquiry study, I employed a purposeful criterion-based sample to select families experiencing an ABI event. I purposively selected families from different regions of the province of Manitoba. Purposive sampling for families experiencing an ABI event is multiplex as criteria for both the individual and family members were considered. For the individual with the brain injury the criteria were: considered medically stable; fully recovered from any acute medical conditions; did not require mechanical ventilation; was living in the community, had English language communication skill capabilities and was able to provide informed consent. A two year post injury criterion was established for the family members. The two years post injury criterion secured family member participants had passed the traumatic and episodic impact of the acute stage of the brain injury (Curry, 2006). In consultation with my thesis advisor, a decision was made to broaden the two years post injury criterion to one-year post injury to include a family who were interested in participating and were deemed to have passed the initial traumatic and episodic impact of the acute stage of the brain injury.

Consistent with the definition the family is who they believe themselves to be “a self-defined group of individuals” (Eggenberger & Nelms, 2007, p.284), ‘family’ consisted of at least the individual member with the ABI and up to a maximum of four other perceived family members. For the purpose of maintaining feasibility, I placed a boundary on the number of family member participants. In accordance with beliefs of a family’s right to self-refer, family members, not I, determined which family members participated. To help family members in their selection process, I provided guidelines for selection (see Appendix I Recruitment Materials). The selection guidelines included, persons who support, share a history and a future, and are committed and caring towards each other. Neither the individual member with the ABI nor the other family members needed to be residing within the same household. These guidelines were written permitting families to include friends as well as biological and legal family member participants. While recognizing children have the potential to be active participants in research, adding children’s’ voices to family research is challenging and complex (Carter, 2009). For this reason, although the original date of the brain injury may have occurred prior to the age of 18 all individual and family participants were required to be a minimum of 18 years of age at the time this study was conducted.

As Robinson's (1995) re-conceptualization of the family unit of analysis was used for this research, sampling strategies were required for both the brain injured individual and their family members. The above noted inclusion and exclusion strategies defined the individual and family population, allowed for flexible family composition and were not overly restrictive.

Polit and Beck (2012) have noted: "there are no fixed rules for sample size in qualitative research" (p. 521). With narrative approaches research can use a variety of different sample sizes (Elliot, 2005). However, a premise of sample size in narrative inquiry suggests: 1) the sample size of participants is contingent on the quality of the participants in their ability to reflect on and communicate their experiences (Polit & Beck, 2012); and 2) the time commitment and close collaboration between participants and researcher makes it unsuitable for a large number of participants (Bell, 2002). Using current literature to help with determining sample size is an issue, given the limited amount of qualitative family research. Eggenberger and Nelms (2007) interviewed a total of 11 families for their research framed by phenomenology and semi-structured interviews. Other family sample size examples include: five (Hissett, personal communication 2016); nine (Kean, 2010); and three (Whiffin et al., 2015). Based on sample size evidence from the literature, complexity of the methods of analysis (within case and across case), and recommendations from my committee members, the sample size for this project was set at six families.

Diversity of sample. All six participating families were unique, varying in structure, culture, and ages. Family structures included; 1) intact biological members (father and or mother and children); 2) blended families; and 3) friends as family members. One family self-identified as Aboriginal. Participant ages ranged from 23-67. Regarding the individual family members with the ABI, their brain injuries resulted from either non-traumatic or traumatic and were diagnosed within a range of moderate to severe. Of the six family member participants that had the brain injury, only one was male.

Recruitment

Six families participated in this study. Recruitment was challenging, and took over one year to secure the sample size. Participants were recruited through community agencies who agreed to share recruitment materials. Recruitment materials included: in person information sessions; online video post; a poster; and as an information item in community agencies' newsletters. Family recruitment was initiated with the chapters of the Manitoba Brain Injury Association (MBIA) including Winnipeg, Dauphin/Parkland Region, Brandon and the surrounding region; and over the year expanded to include: 1) the Stroke Recovery Association of Manitoba (SRAM); 2) the Reh-Fit Centre of Winnipeg; and 3) The Independent Resource Living Centre (Winnipeg). Alternate recruitment strategies were also employed. These included sharing information about the research project with my collegial community network and in a community newspaper. Honoraria funds of $25.00 per participant were provided by research funding received from the College of Nursing Endowment Fund Graduate Student Research Grant and the Fort Garry Legion Poppy Trust Fund Grant.

Setting

The face to face interviews were held at a convenient location that protected the families' confidentiality. All family units chose to hold the interview in a family member's home. Within the setting environment, family members had full visibility of each through circular seating around a dining table or in the living room area.

Data Collection

Data collection for this study was completed using several strategies. Transactional level data was collected through in-depth face to face interviews with individual family units; which included the individual with the ABI and other family members. Data was also collected by ethnographic methods including: family genogram; family group observation sociogram; family ecomaps; and field notes.

Demographic data was collected from each family participant in the form of a family genogram (Appendix F) in order to describe the sample characteristics. This data included participants' ages, relationships statuses, parenting status, living arrangements, diagnosis of brain injury, time since injury, and cultural-ethnic group self-identity. Those family members who did not participate in the interview were also included on the genograms. As well, data was collected on how family members chose who would participate. To augment the transactional level data collected through the interviews, a family group observation sociogram (Appendix H) was used to collect interpretive level data concerning the communication and attachment patterns between family members. Individual participants' emotional tone and body language was recorded on this form. Information about the family's involvement with other external systems (i.e. health care organizations) and social networks was produced with the family through eco maps (Appendix G). This data also included the degree of contact or connection with systems external to the family.

The interviews were digitally audio-recorded and transcribed verbatim through a designated transcriptionist. I reviewed each family unit transcript against the audio recordings and corrected when necessary. Videotaping was considered for this project, however; as transactional data collection was also informed by additional ethnographic methods, the decision was made to not use video recording.

The interviews began with introductions and a reiteration of my professional history and at the same time emphasizing my role as a researcher. Signing of the informed consent form by each family participant followed re-clarification of confidentiality and anonymity (see Appendix B for informed consent). The $25.00 cash honorariums were given to each participant after the informed consent forms were signed. The formal interview started with the collection of demographic and ethnographic data. During the interviews, family members added to the genogram but not present in the interview were included, as I asked circular questions (Wright, & Leahey, 2009) requiring family members to think how the missing member would have responded. I wrote extensive field notes augmenting family interactions from the group sociogram and nonverbal behaviours immediately after the interviews. In addition, I kept a journal to record my reflections, observations, reactions, and other methodological musings.

In qualitative interviews, there is a personal interaction between the researcher and the participants. In interactions with the families I adopted a family-centered and family strengths-based approach, framing the interviews in the context there are no right or wrong responses as viewpoints by all participants are considered valid (Horowitz, Ladden, Moriarty, 2002). Housing the ABI event within the family and not labelling the individual as brain injured can also be viewed from a strengths-based perspective. I employed measures to reduce any perceived or potential power inequity between the interviewees and myself, through encouraging mutuality, effective rapport building, and clearly defining the researcher-participant relationship. As well, I practiced reflexivity about the influence of the researcher on the interview, established equality through interpersonal communication skills, and respected the family's story as they wished to share it. In recruitment presentation scripts and verbal introductions to family members I shared a brief synopsis of my own experiences living with acquired brain injury for the purpose of rapport and trust development. However during the interviews, I was very cognisant to separate myself from the participants' experiences, thereby resulting in data that reflected only the families' experiences. I maintained a commitment to hearing participants' viewpoints, and demonstrated sensitivity to a participant's need to take a break or conclude the interview (Eggenberger & Nelms, 2007; Riessman, 2008). The outcome of using a family-centred strengths-based approach proved advantageous as evidenced by one family' response: "*Jane, not only did you get the information from our family you needed, but all of us feel it benefited us as well. We all mentioned how comfortable you made us feel*."

"The goal in narrative interviewing is to generate detailed accounts rather than brief answers or general statements" (Riessman, 2008, p. 23). Narrative research interviews are considered to be conversations between speakers, building stories through the use of open ended questions (Riessman, 2008). During the interviews, to initiate the process of narrative opportunities, the premise of Lieblich et al's (1998) life story stages was used to help families structure their narratives around their experiences living with ABI. Narrative structure is deemed helpful in allowing participants to answer in ways they find meaningful (Riessman, 2008). I asked families to think about their life experiences with ABI as three life stage chapters in a book about their family. The first chapter was about their family life before the ABI event, the second chapter is now – living with ABI, and chapter three concerns their future family life. For each chapter, I provided the initial narrative conversational opportunity by prompting the family with opening prompt such as: "Tell me about a time in your family before the ABI event that reflects who you are;" "Tell me about a time after the brain injury that reflects who you are as a family now;" and;

“tell me about how you envision your family’s future.” Some families found the open-endedness difficult in finding a place to begin. When this was the case, I followed up with an alternative probe and or question: For example, “Tell me about a particular family ritual…;” “Describe how you functioned, how you were together;” “If I was a fly on the wall what would I have seen, heard?” “Tell me about what has changed in your family.” As their stories unfolded and particularities arose, I added further probes and questions to achieve clarity or to encourage them to continue. Each family unit was also asked to tell me about their experiences with the health care system. As this study was informed by ambiguous loss theory it raised the risk of imposing a structure on the participants’ accounts that was not reflective of their experiences. To refrain from this, I attempted to avoid probes in which I used concepts from the theory. However, with one family, as I became attuned to what they were saying, I defined and named ambiguous loss and probed if this term made sense to them. Upon reflection of my investigator role in co-creating the narrative, rather than biasing their responses, it appeared that by naming a form of loss, their own experience was affirmed, as they proceeded to describe their loss experiences. Quotes from the findings are verbatim representations of the language of the participating families.

Conscious efforts were made to elicit responses from all family participants. I posed questions directly to specific family members to ensure all family members had an opportunity to respond. However, at the same time I remained cognizant I did not want to pressure a family member to be verbally responsive. Therefore, my attention was also focused on their nonverbal communication as it signalled they were engaged in the interview.

For the purpose of following up families’ reflections from the initial interview, clarifying any uncertainties and any additional perspectives they wished to relate, families were offered the choice of a second interview following their review of their individual transcripts; however only one family opted for this option. To help facilitate each family's reflections I reviewed the transcripts and provided family members with individual summaries of their intact statements pulled from the original transcripts for them to review. I attempted to maintain a timely turn around time between when I received the transcripts and forwarded the summaries to the families.

Data Analysis

Narrative analysis, while having aspects common with other case-centered approaches, relies on accounts that are analytically treated as whole units rather than fragmented into coded categories as evidenced in other qualitative approaches (Riessman, 2008). In examining how people make meaning of life experiences, stories are the object of inquiry, and thus are not fractured (Polit & Beck, 2012). Family data analysis is a complex process (S. K. Eggenberger personal communication, May 25, 2016). In studying families, data analysis needs to capture issues and concerns and relational processes that are shared between family members (Chesla, 1995). Methods of family level data analysis are not readily identified in the literature (S. K. Eggenberger personal communication, May 25, 2016). For this research project, the transactional level data was analyzed mainly using the model of analysis developed by Lieblich, Tuval-Mashiach, & Zilber (1998), and processed through two layers. First, each family unit transcript was analyzed separately by a within case analysis, followed by an across case analysis. Following completion of the interpretive within case analysis, individual interpretive family synopses were generated (Appendix A for Interpretive Family Synopses). These synopses reflected my global impressions of how each family made sense of their experiences living with ABI.

Interpretive within case analysis. Interpretive within case analysis was accomplished using a combination of cell classifications. Lieblich et al. (1998) acknowledge in the reality of data analysis there is no clear separation of cells and researchers need to make decisions about the size and breadth of cells. For the purpose of pragmatically containing the analysis for this thesis, the decision was made to adhere principally to the holistic-content cell, however, as these families' transcripts held unique attributes, elements of the holistic-form, categorical form, and categorical-content modes of analysis were incorporated in the analysis. Completed family genograms, sociograms and ecomaps also informed the within case analysis.

The holistic-content cell mode focuses on the content of the narrative (Lieblich et al., 1998). The researcher directs attention to what is said and what the content means (Riessman, 2008). With an open mind, each family transcript was read multiple times looking for story 'foci' and reading for overall global impressions. Transcript readings were maintained throughout pattern and thematic identification, and writing on the findings in chapter four. While the life-story chapter structure of before the ABI, now, and future helped to delineate a chronological order, further excavation and re-organizing of the data was required to place the data in a chronological storied form. During the initial read, coloured markers were used to track and highlight sections, phrases, repeated words, contradicting episodes, and episodes or issues that were disturbing to the teller(s). This information was later transferred to an excel spread sheet in order to more effectively track the appearance of themes and construct meaning. Analysis of content meaning also led to interpretations of what was not being said. My reflections and musings on global impressions, themes, and potential meanings were also put into writing.

The holistic-form mode of analysis looks at the plots or structures of complete life stories (Lieblich et al., 1998). Elements of the holistic-form cell were assimilated into the holistic-content cell for one particular family (the Carter Family: Appendix A); as their transcript signified a complete life story, and the development of themes were structured around a plot that had a beginning, middle and an end. The categorical-content mode of analysis was used to extract the number of times a particular phrase or statement was being verbalized by family members. The findings from this cell dimension are most notable in the Wilson family synopsis (Appendix A).

The categorical-form mode of analysis concentrates on "discrete stylistic or linguistic characteristics of defined units of the narrative" (Lieblich et al., 1998, p. 13), and also denotes the 'paralinguistic language' (Lieblich et al., 1998, p. 154) of emotions i.e. tears. Elements of the categorical-form mode of analysis were assimilated into the holistic-content cell, particularly when a family's emotions became a part of my global impression. The categorical-form mode of analysis was incorporated in the analysis of the Carter and Stetler families (Appendix A). While discrete linguistic aspects can be considered performative (Wright, et al., 2016), the participating families exhibited performative (embodied) actions as they interacted with each other during the interview that were outside the linguistic parameter. Actions such as: getting up to get a box of Kleenex or walking around; playful gestures; and petting or picking up and talking to the family pet, were referenced on the observational sociograms. Therefore, I entered new territory in going beyond the analysis model of Lieblich et al. (1998), to identify family members' use of their bodies to communicate and interact with each other, that assisted in the development of global impressions. This manner of analysis is most noted with the Wilson family.

Across case analysis. Subsequent to the within case analysis, the across case analysis was accomplished using the thematic analysis approach delineated by Riessman (2008)**.** Informed by the four cell modes of analysis and the ethnographic materials, across case analysis began by focused re-readings of each family case to identify common patterns, assumptions, concepts and differences. Specific language and significant statements or phrases that provided perspectives on families' experiences were highlighted, categorized and placed onto a large chart to facilitate comparisons. This resulted in the development of overarching master themes or narratives.

Identifying common elements across research participants is a well-developed practice within qualitative research (Riesman, 2008), however, the subtle difference with narrative inquiry is that sequences are preserved to keep the story the families' stories intact rather than thematically coding segments. The findings from the across case analysis are featured in Chapter Four of this thesis.

Strategies to Ensure Trustworthiness and Quality of the Study

The purpose of trustworthiness in narrative inquiry research is the same as it is in other qualitative research; to demonstrate "the data are genuine, and analytical interpretations of them are plausible, reasonable and convincing" (Riessman, 2008, p. 191). Trustworthiness in narrative inquiry is a particular issue due to being centered on the premise that stories have multiple truths (Riessman, 2008). Riessman (2008) points out, verifying facts are not important as: "narratives are not factual accounts rather articulations told from particular points of view" (p. 187). Mishler (1990) argued: "Focusing on trustworthiness rather than truth displaces validation from its traditional location in a presumably objective, non-reactive, and neutral reality and moves it to the social world - a world constructed in and through our discourses, and actions, through praxis" (p.420).

Trustworthiness and evaluation criteria for this study was obtained from two sources: 1. Lincoln and Guba's (1985) trustworthiness criteria of credibility, dependability, confirmability, transferability, and authenticity (Guba & Lincoln, 1994): and 2. the four criteria espoused by Lieblich et al. (1998): 1) width; 2) coherence; 3) insightfulness; and 4) parsimony. Although Lieblich et al's (1998) criteria are generically written providing limited strategies; it was important to consider their criteria in determining the rigour of this study.

Credibility. "Credibility refers to confidence in the truth of the data and interpretations of them (Polit & Beck, 2012, p. 585). The following specific strategies were employed to address Lincoln and Guba's (1994; 1985) trustworthiness criteria.

Reflexivity. Reflexivity is a core characteristic of qualitative research (Creswell, 2014). Narratives are invited by the researcher and the researcher is seen to be part of the data as they are an active participant in the construction (Smith & Sparkes, 2009). The result of this co-construction is the heightened potential for the blurring of interpretive boundaries between the researcher and the participants (Riley & Hawe, 2005). Thus, in order to maintain the integrity of the particular points of view of the participants and to monitor ad hoc theorizing and interpretations, reflexivity throughout the research process by the researcher in narrative inquiry is essential (Burck, 2005).

Since I am a family member who has experienced living with ABI, the need to maintain reflexivity throughout the research process was critical. To encourage trustworthiness, I kept a log documenting my thoughts, questions, observations, decisions, and interpretations; as well as conferring with thesis committee members. The audit trail and discussions helped me to identify moments when I may have been prone to imbue my perspective. My background as a psychiatric nurse enhanced my reflective capabilities as the reflective process is a mainstay of the profession.

Triangulation. In qualitative research, triangulation has traditionally been defined as: "an approach to research that uses a combination of more than one research strategy in a single investigation" (Streubert & Carpenter, 2011, p. 349). Contemporary approaches to qualitative triangulation refer to a "crystallization" framework to reflect the epistemological position of constructionism rooted in qualitative research such as narrative inquiry (Richardson, 2000). Crystallization "utilizes forms of analysis or ways of producing knowledge across multiple points…" (Ellingson, 2014, p. 444). To examine evidence about families' experiences living with ABI different data sources were utilized. Data was collected and interpreted from multiple sources including: family unit interviews; family genograms; ecomaps; observational group sociograms; and field notes. I also utilized two analysis approaches to construct patterns across data from multiple participants to craft themes and impressions.

Member checking. Whether or not to use member checking is a point of debate with narrative scholars. Riessman (2008) urges caution as scholars are held more responsible for the validity of their analysis. In a more conciliatory vein, Lieblich et al. (1998) proposes "a process of consensual validation – namely, sharing one's views and conclusions and making sense in the eyes of a community of researchers and interested, informed individuals – is of the highest significance in narrative inquiry" (p. 173). Lincoln and Guba considered "member checking a particularly important technique for establishing the credibility of qualitative data" (Polit & Beck, 2012, p. 591). Although, too much reliance on member checking can potentially compromise the significance of the research findings (McBrien, 2008)

To secure credibility of the findings I followed the counsel of Morse (2015) referring to member checking as giving the transcribed data back to the participants to obtain additional data or revised data. Each individual family member was given a copy of their words taken from the original transcript for their review. Only one participant chose to return a revised transcript with corrections. To safeguard myself from researcher bias, I enlisted my faculty advisor and thesis committee members for their perspectives on the themes that were being generated.

Negative case analysis. To strengthen credibility, Lincoln and Guba (1985) recommend the strategy of negative case analysis; the process by which the researcher considers all cases discrepant or otherwise in refining interpretations. In Chapter Four, alongside presenting evidence

I also exhibited contradictory evidence in the findings; pointing to differences of opinions amongst family members or suggesting an anomaly in the findings.

Dependability. Dependability is the "stability…of data over time and conditions" (Polit & Beck, 2014, p. 323), and this criterion of Lincoln and Guba (1985) was addressed through a variety of strategies. To begin, I checked each interview for mistakes in transcription. To accomplish this, I listened to the audio recording as I read each transcript. Secondly, I developed a standardized method of note taking, in particular the field notes. To make sure there were no inconsistencies with thematic development I engaged in the practice of constant comparison of data against the development of the themes. I accomplished this through memo writing about the themes and their definitions. A fourth dependability procedure concerns investigator triangulation. It is important for a single researcher to have another researcher involved with analytical decisions (Polit & Beck, 2012). My PhD faculty advisor examined and evaluated the within case and across case analysis to ensure interpretations were supported by the data. As this is a doctoral project, the other advisory committee members also provided input, suggestions and or recommendations, about the within case and across case data analysis. The previously mentioned strategies of data triangulation and member checking also contributed to the dependability of this study

Confirmability. The criterion of confirmability is concerned with maintaining objectivity, that is, the "potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning" (Polit & Beck, 2012, p. 585). Using peers to debrief or critically analyze the data adds to the confirmability of the findings (Creswell, 2014). As this is a doctoral project, the researcher's faculty advisor and faculty committee members acted as critical peer reviewers through the process of data analysis. Creswell (2014) suggests the use of an external auditor, someone who is not familiar with the researcher or the project and can impart an objective assessment.

Transferability. This criterion refers to the extent findings can be extrapolated to or have applicability with other groups or settings (Polit & Beck, 2012). According to Lincoln and Guba (1985); “the investigator’s responsibility is to provide sufficient descriptive data so that consumers can evaluate the applicability of the data to other contexts” (p. 316). Riessman (2008) contends “good narrative research persuades readers” (p. 191), and adds to general knowledge by employing evidence from participants’ stories, negative cases and alternative interpretations that can support theoretical claims. To convey the findings, I undertook to write rich thick descriptions using numerous quotations in reporting the narratives and providing detailed descriptions about the setting, participants, and observations. When detailed descriptions are rendered the results become more realistic and vivid allowing readers an element of sharing in the experience (Creswell, 2014). Other strategies included: taking comprehensive field notes, reporting negative cases and alternative interpretations, and documenting strategies to increase trustworthiness (Polit & Beck, 2014).

Authenticity. Authenticity refers to “the extent to which researchers fairly and faithfully show a range of different realities” and “emerges in a report when it conveys the feeling tone of participants’ lives as they are lived” (Polit & Beck, 2012, p. 585). The previously mentioned strategies of thick and vivid descriptions of demographics and context, reflexivity, prolonged engagement, and transcription rigour were retained to support authenticity.

Furthermore, Lieblich et al’s (1998) criteria for authenticity in narrative inquiry research was considered throughout the research study. According to Lieblich et al. (1998) the first criterion of width refers to the comprehensiveness of evidence. Through incorporating the strategies of thick rich descriptions and presenting alternative interpretations, I adhered to this criterion. Coherence, the second criterion, concerns ‘the way different parts of the interpretation create a complete and meaningful picture” (Lieblich et al., 1998, p. 173). Internal coherence was evaluated through the strategies of triangulation and the strategies previously outlined under transferability were employed in the evaluation of external coherence. The third and fourth criterion of insightfulness and parsimony appear to be a combination of Lincoln and Guba’s criteria of transferability and authenticity. Therefore, strategies already documented within these headings were considered as complying with the criterion of insightfulness and parsimony.

Ethical Considerations

Ethical issues are always involved in human subject research. Ethical considerations for this research study were based upon the standards of the *Tri-Council Policy Statement* (TCPS) and informed by three core principles. The principle of respect for humans “recognizes the intrinsic value of human beings and the respect and consideration they are due” (TCPS-2, 2014, p.6). This principle includes the right to autonomy, self-determination and full disclosure (Polit & Beck, 2012). The second principle is concern for welfare of persons. This principle imposes a responsibility on researchers to protect the welfare of participants by mitigating risks and maximizing benefits (Polit & Beck, 2012; TCPS-2, 2014). The principle of justice attends to the obligation of participants’ rights to be treated fairly and equitably (TCPS-2, 2014). “Fairness entails treating all people with equal respect and concern… equity requires distributing the benefits and burdens of research participation in such a way that no segment of the population is unduly burdened by the research or denied the benefits of the knowledge generated from it” (TCPS-2, 2014, p. 8). These ethical principles formed the basis for the ethics protocol of this study, which was approved by the University of Manitoba Education and Nursing Research Ethics Board.

Further, eight requests for amendments were submitted to the University of Manitoba Research Ethics Board to facilitate data collection.

Respect for persons. An important procedure for respecting autonomy and self-determination is informed consent and freedom from coercion (Polit & Beck, 2012). An initial expression of interest cannot be assumed to indicate consent (Stevens et al., 2010). Once a family had expressed initial interest in participating in this study, I spent time fully informing participants about the study in an understandable way, after which they were provided with a written informed consent form (see Appendix D). Families' consents were voluntary and there were no repercussions for not participating. Participants could have withdrawn from this study at any time and they had the right to refuse to answer any questions with no negative consequences or bearing on access to any type of health care service. If a family had decided to withdraw, all raw data collected would have been destroyed. All six family unit participants remained in this study.

Families were informed of the process for disseminating the research findings. A signed consent form indicated their understanding and consent to be part of the study. Consideration of coercion in this study was nil as the researcher was not in a role of authority with the participants and had no prior clinical involvement. The researcher did not have any conflict of interests with the Manitoba Brain Injury Association, the Stroke Recovery Association of Manitoba or any other not for profit community support agencies and funding body. Although the Executive Directors of the community support agencies acted as gatekeeper, as family participation was self-referral, organizational coercion was not a concern.

Concern for welfare of persons. Although complete anonymity is not possible in this narrative inquiry study with face to face interviews, a pledge of confidentiality was given to the participants. Similar to focus group research, participants in this project were asked to respect the confidentiality of all family participants by not identifying who participated and what individual participants shared. The not for profit community support agencies were not apprised of any family participation. The transcripts were identified only by number and included only the initial of the participants' first names. All participants were given a pseudonym for use in the data analysis. Only I had knowledge of the real names of family members and had access to all of the data. Only my faculty supervisor had access to the family transcripts, while thesis committee members had access to data analysis documents and findings. Confidentiality procedures were explained to the transcriptionist, who signed an oath of confidentiality (see Appendix I) and was directed to work in a private space and/or use headphones if there are other persons in the immediate environment who can hear audiotapes of the interview. Interview transcripts, individual summaries, and analysis excel spread sheets were electronically stored and password protected. Field notes and reflective journaling were kept manually in a notebook and stored in a locked cabinet in my home. All identifying information was removed from the electronic formats and pseudonyms were provided. The original completed demographic genogram tools, ecomaps, and group observational sociograms remained as hard copies and were also stored in the locked cabinet. Although family genograms were generated for each family unit, I made the decision to not include them in Appendix A as participants' identities could have been compromised.

Findings of this study are written in the thesis, and will be published in academic journals and presentations will be given locally, nationally and internationally. Given families had strong ties to their home communities, I advised families anonymity could not be guaranteed as they may be identifiable to someone in the community. Nonetheless, it was critical participant identities remained as confidential and anonymous as possible. Each participant was given a first name pseudonym, and each family unit was provided with a last name pseudonym. Identifying data pertaining to age, cause of ABI and level of severity were removed from the demographic data. Instead the generic terms of traumatic and non-traumatic ABI were used to denote type of brain injury. Other identifiers such as names of geographical locations and any specific names of health care organizations or professionals were removed from the findings. When it was not central to the global impressions, quotes revealing sensitive information about family dynamics or other family members who were not participants in this study were left out of the findings or were paraphrased or summarized in a neutral manner.

I also informed family member participants they had responsibility to each other to maintain a confidential boundary by not sharing explicit information about what was said during the interviews. I counseled families to limit their comments to only general information sharing if they decided to tell others about their participation in the study.

Concern for justice. The principle of justice deals with the conscious weighing of benefits and risks for potential participants (Fisher & Anushko, 2008). In the case of living with an ABI event, possible benefits included families learning more about each other’s needs and their responses could potentially be relevant to informing health care practice and education. I had established protocols minimizing risks for potential participants. This study did not focus on a specific vulnerable group as all participants were able to provide informed consent. The potential to experience emotional and stressful responses as a result of telling their stories was discussed. During the interviews when a participant(s) was observed to be expressing a tearful response I asked whether they needed to take some time before continuing, reschedule or if they wanted to stop. Prior to the start of interviews a list of community resources was made available to all participants.

The role of the researcher is not to provide therapy. However, the boundaries between the researcher role and the therapy role can become blurry. The qualitative interview process can provide a therapeutic aspect, as families are able to release emotions in a safe manner, and they can develop greater understandings of members' perspectives (Eggenberger & Nelms 2007). Thomas (1987) explained qualitative interviews and therapeutic interactions share similar characteristics (empathetic responses and active listening), however research interviews differ as they do not engage clients in challenges and the goal is not to induce a change process. At no time in the interviews did I provide clinical information advice or education (Horowitz et al., 2002).

Interview arenas can be described as building safe environments, thus participants may unwittingly disclose other personal information that is not related to the study (Clark & Sharf, 2007). Disclosing other personal experiences may have a dramatic impact on family members if they are hearing this information for the first time. Therefore, if this situation were to have arisen, my plan was to dialogue with the family to consider not continuing and withdrawing from the study. This situation did not arise in any of the interviews. Although suicidal and homicidal ideations are not prominent in the ABI population, as part of the ethics of informed consent, participants were informed of the procedures for reporting abuse, suicidal or homicidal intentions, and, initiating supportive referrals. For a report of abuse (sexual, physical, emotional) involving an individual under the age of 18, I would have contacted Child and Family Services. For a report of elder abuse (sexual, physical, emotional and or financial) I would have contacted the Elder Abuse Consultant for the Province of Manitoba (see Appendix D). In the case of disclosures regarding suicidal or homicidal intent, I would have initiated a referral to a health care professional within the provincial mental health system. However, these situations also did not arise.

Overall, this study posed minimal risks for the participants. Participants were compensated for the potential burden of their time with a $25 honorarium. In summary: the ethical principles of respect for persons, concern for their welfare and justice were reflected in the informed consent, and throughout the research project.

Dissemination of Findings and Knowledge Translation

Rigorous dissemination activities for this research project began with the offer of a copy of the written master narrative for each family unit participant. Participants signalled their openness to receiving a copy of the master narrative by ticking yes and providing contact information on the informed consent form. I will also offer to present a master narrative summary to the not for profit community support agencies that acted as gatekeepers for this study. Auxiliary dissemination activities may include conference presentations and workshops and particular brain injury and/or other health care journal publications.

Research knowledge translation strategies are considered a critical component of any research planning as they are designed to link research findings to practice and policies (Straus, Tetroe, & Graham, 2011; Ward, Smith, Foy, House, & Hamer, 2010). Current literature reflects the growing interest and use of arts-based methods in knowledge development and translation, particularly within the health care disciplines and professions (Kontos & Poland, 2009; Lafreniere, Hurlimann, Menuz, & Godard, 2012; Parsons & Boydell, 2012; Rieger & Schultz, 2014; Rossiter et al., 2008). In the field of health care, arts-based research methods have been used in unique ways to engage multiple stakeholders on important related health care issues, such as cancer, dementia and traumatic brain injury (Parsons & Boydell, 2012). Arts-based approaches to knowledge translation (KT) have been demonstrated to enhance the lived experience understandings of health issues by drawing attention to the experiential and interactive aspects of these issues (Kontos & Nagle, 2006; Parsons & Boydell, 2012). Arts cultivate empathy, critical reflection and promote dialogue and the sharing of stories (Parsons & Boydell, 2012). Rossiter et al. (2008), employed research-based theatre in developing the play “After the Crash”. This play about the experiences of traumatic brain injury, viewed by health care providers, was anchored on the data and analysis from six focus group interviews comprised separately of survivors, family members and health practitioners (Colantonio, et al., 2008). Kontos & Nagle (2006) translated their ethnographic research findings on the topic of selfhood in individuals with Alzheimer’s into a theatre production and disseminated the information to nurses and other health care professionals. Subsequent dissemination of findings of this doctoral dissertation project will involve a separate arts-based knowledge translation participatory action-based project that will be used to move forward on implications for practice.

Summary of Chapter Three

This chapter provided an in-depth discussion of how narrative inquiry was used to explore family experiences living with ABI, and justification for using narrative inquiry methodology in designing family research. Using narrative inquiry methodology with *family* research is considered unique and was a suitable fit in exploring families’ families experience living with ABI. Philosophical underpinnings and data collection strategies were described. Innovative data analysis strategies through an in-depth within case analysis and an across case analysis were outlined. Strategies to ensure trustworthiness and ethical considerations were also highlighted. Prospective dissemination actions were discussed in closing. In the following chapter, the master narrative findings from the across case analysis will be discussed.

Chapter Four: The Findings

The master narrative thematic findings of this study are presented in this chapter. As previously indicated in Chapter Three, the individual interpretive family synopses are presented in Appendix A. Informed by the four cell modes of analysis and the ethnographic materials and using the thematic analysis approach delineated by Riessman and her language of "master narrative" (2008), study themes were derived from the reading and re-reading of individual family cases. Specific language and significant statements or phrases that provided perspectives on families' experiences were highlighted and categorized to facilitate comparisons resulting in the development of the master themes. Identifying common elements across research participants is a well-developed practice within qualitative research (Riesman, 2008), however, the subtle difference with narrative inquiry is that sequences were preserved to keep the families' stories intact rather than thematically coding segments. The master narrative themes (Table 2; p. 99) have been structured to replicate the chronological segments of the three-life stage chapters of the narrative interview process: the first chapter about family life before the ABI event, the second chapter is living with ABI now, and chapter three concerns future family life. The chapters and narrative themes signify junctures in these families' lives, yet these parts are connected to a greater whole attesting to families' experiences as fluid and continuous.

To begin, a demographic description of the family unit participants (identified by pseudonyms) is provided to assist with participant identification and understanding (Table 1).

TABLE 1 Family Unit Participant Demographics

THE CARTER FAMILY:

Allen – father, traumatic brain injury 17 years ago

David – oldest son

Jeff – younger son
THE WILSON FAMILY: May – mother Mitchell – father Ann – older daughter Marie – younger daughter, traumatic brain injury eight years ago Tradder (pseudonym) – family pet dog
THE STETLER FAMILY Debbie –wife and mother, non-traumatic brain injury two years ago Mike – husband Rob – younger son Collen – step daughter Trudy – sister to Debbie
THE MERCER FAMILY Frank – father Margaret – mother Melanie – daughter, traumatic brain injury 12 years ago
THE HOLDER FAMILY Terri – wife and mother, traumatic brain injury 10.5 years ago Brent – husband Matt – son Mona – close family friend Macey – close family friend

THE CROSS FAMILY
Evelyn – wife and mother; non-traumatic brain injury one and half years ago Greg – husband and step-father Shelley – daughter Curtis – son

TABLE 2 Life Story Stages and Master Narrative Themes

Before the ABI Event	Families: A Grounding Force
Now Living with the ABI	a. Losses: Individual and Family b. Family Adaptive Capacities • Capacity to reorganize roles • Self educate • Incorporation of beliefs c. Experiences with the Health Care System: Hospital and Home
The Future	A Patchwork Future: Entering the Unknown

Before the ABI Event: Families: A Grounding Force

Through the narratives describing family life it became clear families were expressing strong beliefs about their identity as a family unit. This theme centers on the belief of connectedness and closeness and is associated with the bonding of its members; leading to a sense of belonging. These families' value of belonging underpins their actions, emotions and patterns of relating and is the grounding force that maintains their commitment to the ‘family unit’. All these families not only voiced the language of connection and closeness but also described activities they engage in together that signifies their bond to each other.

At the very beginning of the interview with the Stetler family, Trudy (sister) stated: “*our family, we’ve always said to ourselves that we were a close family. We like to spend time together, holidays together, things like that.... We’re there for support. And I think we all know that.”* Colleen (step daughter) followed by saying: “*if it’s Wednesday night, we just come for dinner. We make more effort to do things that we do regularly… So, the closeness is there*.” Rob (younger son) and Colleen continued to express what they mean by close. According to Rob: “*You would just have to see it’s very mellow, a very relaxed atmosphere. Everybody that does come around, whether it’s family or not family, they’re made to feel welcome. It’s hard to explain*.” Colleen further explained their level of comfort and acceptance of each other:

> *Like my partner coming over and it’s like how are you doing? Hugs and kisses. You leave, you come in with hugs and kisses, you leave with hugs and kisses. It’s ‘what can I get you? What do you need?’ Get to know each other. And then we get comfortable enough you’re farting around each other.*

According to Melanie Mercer (daughter):

> *We have a close family. Like our family cares about family. We care about people, our other family, not our immediate family but we also have a large extended family. My mom and dad have many brothers and sisters as well. And we meet them often too. And they, their families also. And, it’s like such a treat.*

The eldest daughter of the Wilson family, Ann stated: “*We value each other. I don’t know what I would do without having a parent or a sister around because sometimes you need somebody to* *help you out or tell you you're doing a good job or that you are not worthless*." Even after a divorce the connections between father and sons was maintained. As stated by Jeff Carter (younger son): *"I'd just like to say that it didn't stop the connection that we had. I always had a strong connection with my father. I believe I still have a very strong connection with him. We relate a lot."*

Although family members recounted daily routines that involved family members going their separate ways and doing their own things it was important to come together again and reconnect as a family unit or work out issues as a family. Frank Mercer (father) stated:

> *Then, I just think you would have seen a lot of coming and going. A lot of busyness…we did a lot of travel. And as our children got older, we travelled more. So, you would have seen a family of two working parents with children quite involved in the community and their sports and so on, coming and going. And weekends always brought us together. Work took us away from our family the odd day or a couple of days, but the weekend would always bring us back together as a family*.

Shelley Cross (daughter) explained that being a part of a blended family meant coming together as a family to find solutions to accommodate individual styles:

> *But then a typical day seems like everybody had their own isolated agenda or something that they're getting towards. And it's very different from each other which sometimes turns into pandemonium. Everybody has a different schedule. Somebody's quietly studying. Somebody's playing loud music. But it always used to seem to work out or we'd address the concern and make it work out somehow.*

Part of building connection capacity for these families was evidenced by their stories of spending structured fun times together, whether celebrating family events or going on family vacations. Curtis Cross spoke about birthdays and camping: *"We'll do three months of birthdays in a month or so, and we all get together and do larger family birthdays….one May long weekend we all went out for a three or four-day camping trip.*" Allen, David and Jeff Carter spoke about *"camping trips and being able to go blueberry picking…going off the trails and figuring stuff out*."

The importance and reliance on family as a connected unit was also noted during descriptions of challenging family times prior to the brain injury. In discussion about a time prior to the brain injury when a family member died Frank Mercer stated:

> *Closeness would be presence, actually coming and physically being with you. And not necessarily even saying anything. Not saying, telling, counselling or anything. Just having presence during those difficult times. And that was important having people around. We weren't alone*.

Even for the Cross family, as a blended family, when struggling with marital issues and attempting to integrate family functioning and dynamics, their commitment to maintaining a family unit was evidenced in their actions of seeking help. Evelyn Cross (wife and mother) stated in talking to Greg: *"I think you and I were going through a difficult time, but we had come to a point where we had worked a few things out, so that it was on a repair road….*" Followed by her daughter Shelley who replied: *"We definitely spent some time as a family trying to work on repairing the unit but also helping to make sure mom and Greg felt supported on both sides".*

For the Holder family unit their sense of identity and belonging extended to two friends. Brent (husband): *"Well I think I look at everybody as family, with the six of us would hang out a fair bit together…gather for meals and stuff like that. Our kids were more involved with your kids…so I think we were three families with similarities around kids and ages growing up and hanging out together*." When asked what adjective they would use to describe their family before the brain injury Terri Holder (wife and mother) responded: *“Connected…connected. Interested and involved in one another’s lives, we’re all bright and capable and educated, active and athletic.*” Terri’s words contribute to the identity of this family, as she is describing similar characteristics among the family members.

The families’ stories about their lives together prior to the brain injury depict groups of people in which their family unit identities are based on a solid foundation of beliefs in connection and belonging. It is these beliefs and corresponding actions which ground the family unit as a stabilizing force; rooting them in a clear sense of having value, belonging and attachment that remains imbedded during challenging times in their family lives. The next sections address the findings from Now Living with the ABI.

Now Living with the ABI: a. Losses: Individual and Family

There are three major themes within the chronological segment of Now Living with the ABI. The theme of Losses: Individual and Family will be presented first, followed by the themes of Family Adaptive Capacities and Experiences with the Health Care System: Hospital to Home. A prominent storyline is the range of complications experienced by the individual family member with the brain injury and the impact of these impediments on family members. The range of complications signifies the loss of something believed to have been meaningful or of value. Whether the original brain injury diagnosis was considered mild, moderate or severe each of the individual family members who were diagnosed with an acquired brain injury talked about experiences of being different after the ABI. Their individual experiences of difference were mirrored by their families’ perceptions that their loved one was also not the same as before. To begin the discussion of findings for this theme, first the impairments and subsequent experiences of loss for the individual family member with the ABI will be discussed followed by the families' experiences of loss.

Losses: individual. Even though all six individuals had varying degrees of severity of brain injury and were in different stages of their recovery process they described degrees of cognitive, physical and emotional impairments. Living with these impairments made them different than before the ABI, and while not naming the losses directly, they talked about how experiencing these difficulties impacted on their identity, employment, independence, quality of relationships, leisure activities, and emotional health: all valued areas of their life. The following segment is Terri Holder's description of her experiences:

> *It took many months before I could handle more than a conversation with one person at a time. I think it was probably months, I couldn't talk to you and look at you at the same time. I had to keep my eyes closed or looked down because my brain was overwhelmed with information. I couldn't have a radio on. I couldn't watch television. It was years before I could watch and I enjoy sports, say watch a football game, because there was just way too much going on. I couldn't be part of social things. I don't think I was depressed. I barely coped. It's not so much depressed, I just had to really focus to get through. It was a long recovery, and I started back to work on a graduated return at 11 months, 11 ½ months. I remember the first time I was back on a Sunday I think I did sort of the opening part of the worship and then went and sat down and that was it. That's as much as I could handle. I don't think I stayed at the end because I couldn't handle all the people and so it took a while to kind of work back up to where I was. I feel some of the effects of it but I'm back to work, and I still feel even right now and I'm not going to kind of give into it but, my head will swim if I'm tired or overwhelmed. I used to describe it back then after it*

> *happened that it felt like somebody had turned on a blender in my head. It feels like it's just whirling around. I just want it to stop so I can just focus. I had terrible headaches for a long time, and I used to describe them as like a band type thing around my head. I had lots of trouble with balance and walking, and like I said judging stairs is still challenging. So, the more tired I am the more I have to pay attention to that or I find that I'm falling.*

In Terri's telling of what it is like to live with cognitive impairments, she not only describes the internal sensations of a brain not thinking clearly but also recognizes the longevity of these cognitive impairments and that these impairments caused her to lose work functioning, the ability to enjoy sports and partake in other social occasions. These changes to Terri's functioning level were tied to her identity as she expressed worry about not recovering, not being herself. As stated by her husband Brent: *"Terri's identity is wrapped around her 'brain' - "she leads with her brain*."

As Evelyn Cross is in an earlier stage of recovery (18 months post ABI), for her, living now with an ABI is like:

> *I rely on all of them for everything. That means, it's been getting better over time. But initially it's, I mean not working anymore, and not driving for the last many months. Anything that I was taking on personally was now taken on by somebody else. Not only that, taking care of me. I guess over the year, I've been dealing with anger, frustration and lack of independence. You want to just be back to your old self. And I know it's never going to be the same. I know that. It's your life before stroke and your life after stroke.*

Evelyn is recounting experiencing loss of independence which is impacting on her identity and her emotional well being. Evelyn also is aware of the change in her quality of relationship with her youngest daughter Ellen*:*

> *Ellen has had to take on a huge amount of responsibility that she didn't have before. She's got a key and lets herself in because I could be having a three-hour nap in the afternoon. She has to make her own lunches, get herself organized, there's been a lot of responsibility put on her.*

After his brain injury, and because of cognitive and vestibular impairments, Allen Carter lost the ability to work and had to rely on payments from Workers' Compensation and CPP pension. Marie Wilson has lost long term pre-accident memory, "*I don't really remember a whole lot of stuff, it will come and go, but I don't remember a lot*." For Marie coping with significant cognitive impairments led to an emotional collapse for which she spent time in hospital for suicidal ideation. Marie continues to struggle with independence as she continues to reside in the parental home and remains on unemployment insurance. Debbie Stetler has lost her sense of taste and thereby part of a quality of her life: *"But I just get really frustrated with my eating. I would like to enjoy food*." Perhaps more poignantly, is Melanie Mercer who suffered the most severe long-term cognitive impairments including significant memory and decision-making deficits. Melanie's repetitive telling of a singular event during the family interview demonstrates this disability.

> *My memory is not all there but I have some memories from even way back from when I was a younger child. And I can remember those. But I'm ashamed to say that I cannot remember where my son's school is. And I had difficulty with the difference between my children's school. Like I'm not supposed to go to the men's washroom. I didn't know the difference. And like I've done that a couple of times. I didn't know the difference that I was not supposed to be there. But my children would be with me and they would get embarrassed if that happened, where I didn't know the difference and I was going to the*

> *men's room. I didn't know I wasn't supposed to be there. And it's affected them. Like my injury is making them embarrassed I guess, or ashamed of their mom.*

For all the participants with an ABI, to varying degrees, they are continuing to live with the awareness they are not the same person they once were. A part of their 'old self' is gone or lost and they are attempting to accept how they are now. As Evelyn Cross declared*, "And maybe find a new route. It's not going to be the same path I thought. Yes, a new normal."*

Losses: family. Family members of the individuals with the ABI were also aware of the changes to their loved ones and talked about how they were or are continuing to be affected by these changes. In talking about his father Allen, Jeff said:

> *As for the changes that the head injury has made on us…and I know he has brain injuries with memory loss…and because of the accident that he had, he has buzzing in his ears. Now when there's a lot of people around and a lot of kids that are screaming and hacking and everything else, it makes it harder for him to concentrate, he develops headaches and makes the buzzing more. These things are my father and we accept them how he is. But that's basically what it comes down to now is that we are more aware of his, injuries that he has and the disabilities that he has from his memory loss and his balance. And like all disabilities you get into pieces of depression. He has a disability that won't fade away, and it's a lot harder to fight.*

David Carter expressed how his father's memory loss has had a direct impact on himself. *"I've been married twice, and he doesn't remember either wedding. He remembers going to them, but he doesn't remember anything of that day*". The Carter sons express worry, concern and empathy for their father's changes and yet there is an implied sadness that some important moments in their lives are lost to him and in relation therefore to themselves.

Mona a close friend considered part of the Holder family revealed, as she talked to Terri, how she was impacted by the changes noted in Terri:

> *You had trouble when the groups were large. Where there was a lot of cross table talk. I think, for me, part of my concern was some of the personality changes - this quick to respond with a sharpness that probably hadn't been there before. Sometimes if you're really tired maybe it creeps out. But it was quite evident. There were times that I thought, I hope we get her back.*

Brent, Terri's husband talked about how changes to Terri affected him and their relationship:

> *I was more aware of what the landmines might have been or where they were going to be or coming from. It was just different in the house, she was more unpredictable. Not a big issue but we used to go to movies frequently, well that was definitely out of the question. I became more conscious of social activities and what we could and couldn't do in terms of noise and timelines.*

Brent and Mona were observing changes to Terri's personality, missing the old Terri and questioning whether she would return to her old self or be lost to them.

Greg Cross conveyed feelings of frustration at the lost ability of his wife, Evelyn to effectively communicate: *"I would say, 'are you with me?' Like look right at her, 'are you here?' Because as far as I was concerned I was talking to a brick wall. There's nobody there. Hello. And I would say that to her, and she'd turn into 'oh, yea, yea'. 'What were we talking about'.*"

Family members also expressed differences in how they were impacted by the changes in their loved ones. Mike Stetler, Debbie's husband expressed: "*Yea, it's her short- term memory. I have to deal with it all the time. So, we're going somewhere, and we were getting our pool chemicals. I say, 'you got everything?' I says, 'make sure you got everything. Don't sit on the* *couch. Do walk around, look around.' We get all the way, a little ways down, and Debbie says, 'oh I forgot the book.' I says, 'did you?' I says, 'make sure.' And she gets mad at me because I keep reminding her. She tells me, 'I know. I know. You don't have to remind me so many times a day.' And I says, 'start writing notes because you have to.' Put it this way. If she's going to go grocery shopping she don't have a list, she's going to come with half the stuff back. It's just the short-term memory*". While Collen, Debbie's step-daughter describes a different experience of Debbie's memory issues:

> *I do find the memory though is lapsing a little bit, but it's so minor. It's not something that would affect me. I just get to rehear a story. Sometimes she'll repeat some stories like 3 times but it's not the end of the world. It's not something I'm going to be affected by it.*

For the Carter, Stetler, Holder and Cross families the suggested experiences of loss are about degrees of loss as the initial acute impairments experienced by their loved ones are now residual or are continuing to improve at the time of the family interviews. However, for the Wilson and Mercer families their sense of loss is significant and permanent. For both of these families the language of loss was identified and named. As May Wilson described:

> *When Marie had that accident, it was like we lost a family member. After the accident she was a different person. We have never really known what she would have been like before her accident. Who she would have been like? What she would have been like? Who she would have grown up to be? We'll never know that….*

On behalf of their grandchildren, Frank and Margaret Mercer expressed*: "The children…our grandchildren, they lost their mother"*. The Mercer children have lost a mother (Melanie) who can no longer be an effective parent, and for the Wilsons they have lost the Marie that could have been. These two families recognized other losses they had experienced. *"For*

Melanie all her friends abandoned her"; "Marie lost a lot of her friends. They kind of basically turned on her…after awhile they just stopped being her friends." Friends were not the only ones to disappear. Margaret Mercer noted: *"Even during that time for the first two years, I noticed my family didn't always come around*, *I always felt they were suggesting well it's your problem, you stay with it now*." May Wilson recounted experiences of social isolation: *"We don't really associate too much with friends as much as we used to"*. Shelley Cross also understood a loss of societal support:

> *If it was just paralysis on one side, then people give the extra time or accommodate or hold open doors or whatever the case would be that way. And if they need physical support people support them. But it's the same thing as with a mental illness, when you don't see the situation, it's hard to empathize or understand what's difficult and different.*

For each individual brain injury event and the resulting range of complications the participating families acknowledged changes and differences to identity, relationships, social activities and societal supports which have created an overarching sense of loss. The next major theme to be discussed within the life segment of now living with the ABI is Family Adaptive Capacities.

Now Living with the ABI: b. Family Adaptive Capacities

The second of three major themes in Chapter Two: Now Living with the ABI is Family Adaptive Capacities. Families' narratives reveal a powerful thread of strength and resiliency as they cope with the ABI event. The coping these families exhibited moved beyond a coping of subsisting or survival, rather their strength and resiliency is evidenced in these families' abilities to build capacity to effectively adapt to change. These families demonstrated the capacity to: reorganize roles; self educate; and incorporate beliefs that further engendered acceptance and solidified their sense of belonging and identity as a family unit. These abilities show these families to be responsive and consider the needs of all family members while retaining the similar mechanisms for family function and structure. The findings for this theme, family adaptive capacities, will begin with the presentation of the capacity to reorganize roles.

Capacity to reorganize roles. All family members take on roles usually identified by their position in the family structure (i.e. parental role, child role, sibling role). In standard family processes these roles grow and change based on typical family life cycle development. For these families living with ABI, usual family role processes have been significantly interrupted or prolonged. The participating families' capacity to reorganize roles is displayed in their ability to shift roles, specifically from; child to parent; husband to caregiver; grandparent to parent; and friends as caregivers.

Child to parent. Several of the participating adult children family members to varying degrees undertook aspects of the parental role by providing substantial support and encouragement to their parent and assisting with daily activities that would have previously been in the domain of their parent. The one exception was Matt Holder who lived in another province during most of the years Terri, his mother, was recovering. Ann Wilson talked about how she supported her parents; "*We (her husband and herself) were the ones looking after Marie (her sister) if mom and dad were at work or whatever.*" This child to parent role shift was most prominent with the Cross family as Shelley Cross affirmed her role change by expressing:

> *I would say that my brother and I have more communication and contact. Like 'have you talked to mom?' 'Have you checked in?' 'Have you talked to Greg?'... in terms feeling compassionate or that sense of empathy, my mom, her life has changed for such a drastic amount, and I still could not fathom living in her shoes for that day…*

Shelley continued to describe what she was doing to support her mother:

> *I don't mind going grocery shopping. I did the Christmas shopping this year because the thought of going to stores, waiting in lines, it's too much, too many tasks all at once… But there's also been times when Greg was on his canoe trip that Ellen before bed, I'd say, 'hey what do you do?' 'You're about to go to bed. She goes, stove's off, doors locked, windows closed'. OK. And it was a way for us to check because she was just doing a quick little check because I know if Ella's going to bed, mom's probably going to follow in about 20 minutes. All those things were ready just in case. Because Curtis and I wouldn't always stay until mom was going to bed. We'd sort of do the dinner thing and then go from there…*

For Shelley, her support also included a family trip across parts of Canada.

> *We went on this road trip together. My grandma and my mother who has just had an ABI and barely has a driver's license and they tell me they're driving across Canada and they're taking my baby sister with them. I had zero desire to go on this trip but it just sounded like a terrible situation. Sure enough I go on and end up being the mediator for a lot of situations. In some situations it's like the blind leading the bind. They go into Costco. One of them can't hear when there is an alarm and one of them was too scared from the lights to know what's going on in certain situations.*

Shelley's narrative reveals an adult daughter who is trying to empathize about what it must be like for her mother, and offering support by checking in, monitoring, advocating and protecting her mother and younger sister while completing daily household activities – all behaviours a parent would exhibit.

Husband to caregiver. For the Stetler, Holder and Cross families, it was the female of the marital dyad that had the ABI. For Mike Stetler, Brent Holder and Greg Cross their role as marital partner veered in the direction of more responsibility in taking care of their spouses; responding to and managing their illness needs. Through their own descriptions or the reports from family members, Greg and Mike's experiences of the shift from husband to caregiver are prominent, while this role shift with the marital dyad of Terri and Brent Holder took on a more contradictory form and will be discussed separately under the heading friends as caregivers.

Greg Cross clearly acknowledged the transition to caregiver and its impact on him.

> *I am the caregiver at this point. And I'm okay with it. There was a time, when I literally had to be around all of the time. I basically, in a sense, you take your own life and you just sit it on a shelf somewhere and forget everything that you do. And now you're a caregiver for somebody. And you do it because you care. That's why it's a caregiver. But that wears on you after a while. And the little things that you want to do, that you always did, and you can't do anymore because they may be external pressures that she can't handle.*

Mike Stetler's change to caregiver was talked about not by him but other family members. According to Trudy, Mike's sister in law:

> *Mike takes a lot on himself. He is independent, won't ask for help and often won't accept it if you offer it…So I worry that Mike is going to be too stressed and things like that. But I think all of his efforts, that he's put into the care of Debbie has shown.*

Colleen, Mike's daughter, also recognized the potential stressful experiences as her father adapted to the role of caregiver:

> *…dad trying to figure out what he can and cannot do for her. I feel at this point, they have worked out a lot of those kinks. He'll be like well I'm not going to make all this food because she's not going to eat any of it. And they joke about it now. But it was stressful.*

> *Like him saying, 'why can't you eat this?' 'Why don't you try that?' ''You need to do this now.' It's gotten better.*

For Mike and Greg, the transition from husband to caregiver was at times all consuming and stressful. However, capacity was demonstrated through their willingness to accept this role change and work at problem solving how to continue functioning in this role and yet maintain some sense of themselves. Both men were able to negotiate times in which they could spend doing activities important to them; for Greg it was playing hockey and camping in the woods, for Mike it was working on cars and fishing. Greg Cross explained how he negotiated 'me time':

> *While I think she realized some of that, and we had discussed those things. And those are things that have made her understanding of my position, because now representing what is important to me and maybe even this amount because that's all I'm getting as a caregiver is huge. So, her respect for my going to hockey and that I've got to get out. I take a canoe trip with my friend every year. And we go out into the woods and we go away for 10 days or more in a canoe and just live in the woods. And it's, it means everything to me. She was very nervous about me leaving because I'm leaving and who's going to be here in case anything happens. But we made it work and we set up systems for the kids being around mothers-in-law and what it allowed me to do is to go away and to be alone and be outside of that caregiving moment where you're on it 24/7. That has made this whole thing that much easier to continue to give 100% or 98% towards what you can do to help.*

Grandparent to parent. This role shift from grandparent back again to parent specifically fits the situation encountered by Frank and Margaret Mercer. Instead of being in the position of just spoiling their grandchildren, when Melanie had her ABI event, they needed to reclaim parental duties and functioning. For Frank and Margaret this adjustment was fraught with emotional ambivalence alongside the recognition their grandchildren required parenting as Melanie's ability to parent was severely impaired. Frank and Margaret's words eloquently communicated their experience:

> *Well Margaret and I were getting ready to retire. We were transitioning so we had moved trying the condo living. And we were living in a condo and when we finally decided that we needed to become more fully involved with our grandchildren and our daughter, we walked away from our jobs basically. We retired. Some people call it a retirement. Well I left first. And we left the condo living. And we moved into this house here with our daughter and our grandchildren. Then we go, just like we came for the long weekend. We brought our clothes, we did not bring any of our belongings. We put it in storage. And we had a long stay and we're still here. And our grandchildren used to say, 'grandpa, grandma, when are you leaving? Oh, soon we'll be doing that.' But we actually didn't want to take over the family, Melanie's life. We wanted to come be supportive parents. We have some of our own belongings here now. But we weren't moving in and taking over. And so that's how we tried to assist Melanie by moving in with the family and we sort of took the position if our daughter was injured and our grandchildren were injured and the whole family was that we should make sure that our grandchildren at least had a good chance of succeeding. So, we became the strong support for them. Like I said, taking them to the lessons, music lessons so on and so forth. So, we didn't just become the grandparents, we also became the caregivers and that's what Margaret was talking about. I'm not really retired but I am paid by public insurance to be a caregiver instead of them hiring someone else. Because we, as grandparents, had to do all the school interviews. We had to ensure they went to school...*

Margaret added her perspective:

> *… don't know if it's, in some ways I felt like, a strict parent but at the same time not wanting to because, you spoil your grandchildren. So that was difficulty in some way, and yet they do require some discipline. In earlier years if I was trying to discipline them Melanie would step in and take over and then they got really scared. But as time went on they're now young adults. So, it's a little different now.*

Frank and Margaret's role shift meant putting retirement plans on hold and as they did so they built capacity by accepting this situation, prioritizing their daughter and grandchildren and finding ways to regain the authority and responsibility of being supportive parents.

Friends as caregivers. As noted previously Brent Holder's role as caregiver was not readily identified. Rather, the role shifting that was perceived was an exception, because while Brent worked long hours as a minister, it was two friends Mona and Macey who took the role of friendship and extended it into the role of caregiver. As described by Mona:

> *For me, as her friend, and of the rest of the family was not to do anything but absolutely give her and them whatever the support they needed at any time. I think that was primary just to be there whenever she needed it because she was the one with the brain injury. And now more so I understand about the injuries and things with the brain that you don't see. But it's very real and it happens and really all you can do is to support a person in whatever way… I think sometimes making a meal. Bringing a meal over or saying, come and have a meal even though Terri might need to go upstairs and lay down for a while.*

Macey talked about her involvement:

> *It was pretty much every day or twice a day. I think for me and this is going to be quite selfish, but I think it was for me the deepening of friendship and the strengthening of our friendship over many, many, many cups of tea. And just sitting. Don't think we had too*

> *many glasses of wine back then. I think it was mostly tea. But sometimes in those moments of just sitting and the quiet, the quietness of the silence and not, not feeling that you have to say something as just being there. I think I gained a lot of knowing Terri even more, and Brent.*

While directly talking to Terri, Macey added:

> *Well also part of that, the chapter that you were in, managing two challenging parents with major health issues that were really declining. And that certainly added to the stress. I think as friends, close friends, it was obviously a very heightened concern. And feeling like you wanted to fix it. And make that go away what she was struggling with.*

As friends, Mona and Macey became the emotional caretakers of Terri and Brent sharing more emotionally intimate parts of their lives (worries, frustrations and anxieties), becoming an integral and essential support system.

One anomaly in the reorganization of roles occurred within the Wilson family. May Wilson's role as mother was heightened as she became the main parental caregiver for Marie as her life was consumed by the impact of the youngest daughter's ABI event. As explained by May:

> *I would tell somebody that I have a fulltime job and I have a part-time job. My fulltime job is running her to all of her appointment, and my part-time job was my paper job. When he was off work, he would help. He would, if I just wanted to get away from them or whatever, just even go get milk or something or whatever, he would stay with her if he was here. Because I mean we couldn't leave her alone.*

To adjust to living now with ABI, these families showed their strength, resiliency and commitment to the family unit by undertaking a reorganization through a series of simultaneous occurring multiple role shifts or role emphasis. The next section will focus on the family adaptive capacity to self educate.

Self educate. The onset of the ABI event was for all the participating families their first and only exposure to this diagnosis. Margaret Mercer could have been speaking for all family participants when she aptly stated; *"I realize how little I knew about brain injury and the symptoms and how to deal with it. I found out how little everybody else knew."* Several families demonstrated resourcefulness by educating themselves about brain injury; acquiring knowledge of what happened and developing understanding and awareness of what to expect and or anticipate. Shelley Cross articulated this process: "*I think as a family, when mom was in the hospital, we did things like send scholarly articles and research and we were trying to educate ourselves as fast as possible in that situation."*

Family members also talked about the importance of sharing their knowledge. In the Carter family, Allen took the lead on educating himself and his sons. During the Carter family interview Allen shared copies of recent articles about brain trauma that he had printed.

> *I'd like to educate as many people as possible. If I can educate my kids on different things about this, it's going to benefit them in the long run. They're going to come across somebody else and at least they can understand and maybe make some suggestions or, be able to talk to the person. What I'd like to see, like with the family, with just about anybody that I can get in touch with, is the awareness of what brain injury is and how much you have to go through.*

According to step-daughter Colleen Stetler, Debbie also educated herself and her family on the particular form of brain injury she had which helped supply an important answer, so the family could make sense of what had happened.

Self education as a coping strategy was utilized by the participating families to build capacity to effectively adapt to change. Knowledge attainment is important in developing understanding because with understanding the families can continue preparing themselves for managing living with the ABI. As stated by Shelley Cross, *"I think we're still learning."* The next section will focus on the family adaptive capacity to incorporate beliefs that helped them to effectively adapt to living with ABI.

Incorporation of beliefs. Beliefs are personal attitudes that allow for meanings to be considered as a basis of human emotions and actions. These families revealed mutually shared interpretations or beliefs about the brain injury event that aided them in effectively coping with living with ABI. Thus, further engendering acceptance and solidifying their sense of belonging and identity as a family unit.

From the perspective of the Carter family the ABI event was a near death experience that provided Allen with a second chance to re-evaluate his life and reconnect with his sons. Jeff named this belief a 'Blessing'.

> *You know as bad as it sounds, this was kind of a blessing for our family because of his accident. We're more understanding of each other. It kind of fast tracked us to where we are right now. Where we do stuff for each other and we want to do things with each other.*

Debbie Stetler also held the belief her brain injury was 'a blessing in disguise' because it helped her re-asses her personal ways of coping and appreciate family values of support and acceptance.

> *one of the things that might sound really crazy is, this was a blessing in disguise because … it was just like a slap upside the head saying, that's enough. I think since this has happened, I've learnt how to cope a little bit better with stressful situations. I think for me,*

> *what changed the most, what I realized is after this happened, just I guess the love and support from all of them. I guess I was questioning it. I just watched when I was in the hospital how much strength I got from them, much encouragement and how much love they showed me even today.*

The rest of the Stetler family embraced Debbie's belief as they saw her change and reaffirm her connection to family and therefore their connection to her. In speaking directly to her sister during the interview Trudy acknowledged.

> *Like I have noticed that since the ABI and your recovery, you do seem to handle problems differently. Like mentally she seems to be able to process it better, deal with it, either move on or, or handle it or whatever and it makes me feel good to see that happening, and I think the impact it's had on me is that I'm happier because I think she's happier as a mother, a wife, a sister.*

Rob, Debbie's son also agreed; *"You know that's funny, I was going to say that. I don't have to worry about her all the time worrying about bullshit problems"*.

The Wilson's family mantra of 'one day at a time' and 'just do it' attitude became more pronounced following the ABI event of their daughter Marie. These corresponding beliefs helped family members to cope with the stressful times during Marie's recovery. When the eldest daughter Ann described all that her mom May had to do;

> *I think because mom had to take Marie to all these appointments and she had to work her own job and then she had to be with Marie, it takes a toll on a person. But she managed and got through it somehow.*

May's response was to shrug her shoulders and say, *"One day at a time like dad said… that's all you get. It's all you need. That's all we got…we just did it. I didn't have time to wallow. My whole* *motto was you just do it."* Their belief in one day at a time helped the Wilson family accept the ABI event. As stated by Mitchell: "*That's how it is. You can't change anything. You can't go back. We'll just never know what would have happened".* And followed up by Ann; *"But this is now and this is how it is and you can't dwell on what would have happened because you can't live in the past".*

Another Wilson family belief that arose following the ABI event and reflected how they are as a family now is the belief of being cautious and careful.

> *You know any time we go away, or anybody goes on a trip or holiday, we don't say anymore, enjoy your trip. We always say be safe. Be careful. A safe trip is a good trip. Because you never know…somebody leaves you don't know what is going to happen. I think we're just a little more cautious. We're careful.*

Frank Mercer singularly expressed the belief that the ABI event was a 'gift'; affirming their capacity for coping and identity as a close family. *"But we get a gift. We get to spend a lot of time with our grandchildren. So, there are some fringe benefits from that too. We get to see them grow and not everybody gets to do that so".* Frank also raised a challenge to the belief that lives have chapters. Instead he saw life as having beginnings and endings.

> *You sort of call it chapters. I call it beginnings and endings. I always say, in our life we had beginnings and endings. You start, Grade 12, it's over. You do university, it's over. You work, it's over. You move to a town and you're there for a certain length of a time. It's over. Changes everything.*

Frank believes the ABI event was the start of a new family beginning because it *"changed everything".*

> *Not only did our daughter get injured and was sick. With that comes change to everybody. It's injury to everybody. The children. Injury to Melanie my wife and also to myself, and also to our family. And the other one was also friends. That affected them.*

Participating families expressed beliefs were prominently positive in nature. Whether characterized by faith-based language, ideas of living in the moment, or the commencement of another life path, these belief systems enabled effective adaptation to living with the ABI by reinforcing the families' bonds to each other; the grounding force behind their demonstrations of strength and resiliency.

Now Living with the ABI: c. Experiences with the Health Care System: Hospital and Home

This third major theme of the life segment now living with ABI explores the experiences families had or continue to have with the health care system from initial hospitalization to community treatment and supports. While families' experiences are described in this theme, this theme is also about attending to the missing element in their experiences and interpreting this omission. Overall, families' experiences of the health care system varied depending on the cause of the ABI, the severity of the ABI, the recovery process and the degrees and kinds of service involvement (i.e. mental health services, community rehabilitation services, community support groups, and or insurance agencies {worker's compensation or vehicle insurance}). However, the similarity in families' experiences was the distinction between acute care and rehabilitation and community-based care. Family members spoke about the decrease in resource availability following acute care. Evelyn Cross explained:

> *I think I've been very fortunate to have really good doctors, really good advice and care. I felt I've been in very good hands. More recently, as soon as you're out of the hospital, it's*

> *a different story. Then you're on a waiting list. And you're just a number on a list somewhere. Not sure when you're going to get the therapy.*

Frank Mercer stated:

> *I was talking about from the time of the accident during emergency and intensive care. Very good during the time of just coming out and observation very good. But when you get into recovery, that's when the health care system starts to deteriorate. And when Melanie was in recovery, which she was in a coma for 17 ½ days and then in the hospital for 4 ½ months. And that's where they're understaffed. That's where they haven't got time to spent time with the patient. And that's when they don't have time to deal with any of the effects that a patient may have. Melanie with her injury, would maybe wander away. So, they had her tied to a wheelchair. And then because if she started to yell for things or whatever, they started to sedate her to slow her down. And that's when we became more involved as parents. So, Margaret would go 8 o'clock in the morning when she woke up and spend all day with her so they didn't have to sedate her. And I would go at 4:30 and stay till midnight until she went to sleep. And we did that for 4 ½ months as parents. That was just so that the health care system would not sedate her and drug her up. And as it was, they did drug her a little bit. And when we got home we had to wean her off of it. But that's their way of dealing with patients of just quieting them down which we didn't really want to happen to our daughter so we were more involved with the healing there. So that's where the system then is, it starts to deteriorate I would say in that, in the hospital and that shortness of staff and being able to be with people when they're healing. So that's what we found and noticed. So, we were more involved as a family with the healing being there.*

Families involved with insurance service providers considered themselves lucky because resource availability included financial support for additional rehabilitation and caregiving costs. However, these resources were also limited. The Mercer family had to advocate for additional funding and resources when insurance support was denied or ended. Margaret recounted:

> *You phone people. You gotta write. You go there, you go here. You get moved around and stuff like that. The difficulty with the doctors. Now I found the doctors did not cooperate. They don't want to cooperate. And then the other one is trying to get help, counselling for my grandchildren. 'What about them?' Insurance simply said, well no, we don't cover the children, this is just for the client. So, then I made an effort, how many different places I called to try and get help for them. Couldn't do it.*

Families also noted a reduction in resource availability in rural centers. May Wilson contended;

> *But you get out to these smaller towns, and there's not as many supports or, or no supports out there. They probably would need more supports out in the smaller towns because a lot of these people have to come to the bigger places for the supports. But to have only one (support worker) to how many people that need that support workers…And I think a lot of these support workers and a lot of these health care workers, they're overworked.*

As they shared their experiences within the health care system, the Stetler, Wilson and Cross families touched on how health care professionals engaged with families. Mike Stetler communicated; *the hospital is run really good. The gamma surgeon actually showed us exactly what he did and what the problem is and the gamma knife thing that had to happen."* May Wilson spoke about all of the appointments; *"Marie had a lot of appointments. I had to write every little thing down because she had so many appointments."* And Mitchell Wilson followed up by saying; *"The insurance company would book appointments through (name of city). They wouldn't relay that on to us and they would phone to confirm an appointment and May never had any knowledge of the appointment."* Shelley Cross recounted a time when her mom was still in the hospital, the family requested that Evelyn be allowed to audio record (using her phone) the doctors' conversations with her because she could not remember what they were telling her and therefore could not relate the information to her family. While some of the doctors allowed the recording, others did not. These descriptions give the impression health care professionals are primarily engaging with the individual in care.

On one level the findings for this theme indicate these families experienced resource inadequacies within health care systems and health care professionals focused on the person in care. Another finding is an interpretation extracted from what is not being talked about, what is being omitted. What is missing is the element of how families as a unit view themselves in relation to the health care system. For families their involvement with the health care system is in relation to the individual. Their focus is singularly centered on their loved one with the ABI or a family subunit (i.e. the Mercer grandchildren) and their cognitive, physical and emotional energies are directed towards trying to ensure resources are made available to those individuals. It appears the family does not think of themselves as being part of a total care package. Their experiences do not include family members talking about being apart of the treatment process in which health care professionals collaborated with them and engaged with them as being experts on their own family members or asked about family needs. It could be families are mirroring the actions of health professionals and a system that focuses on the health of the individual not realizing or unaware there can be alternative health care practices.

This concludes the section on the findings for Now Living with the ABI. Three major narrative themes were explored: Losses; Individual and Family; Family Adaptive Capacities; and Experiences with the Health Care System: Hospital and Home. Each of these themes are representations of the manner in which these families are currently living their lives and how they will be continuing to live in the days ahead.

The Future: A Patchwork Future: Entering the Unknown

Families thoughts about their future lives are enveloped by the dominate force of living with ABI. This third and final master theme illustrates how living with the ABI continues to influence families' thoughts and feelings about their future. In this theme, families expressed a patchwork of thoughts: hope and optimism for continued recovery; successful progression through ongoing life stages as life carries on; while also conveying undercurrents of fear and worry about legalities of arranging for future care and supports, and potential for occurrence of another ABI event. However, no matter what their thoughts and feelings about the future these families continued to emanate their future together as a collective force.

As Allen Carter stated "*not really a huge difference in what will be happening',* Jeff added: *I think it's a progression of what it is right now. We're just moving with my dad to see what's happening. So, I guess we'll take it as we see it. But we'll always be there.* Mitchell Wilson began by talking about a future life stage change but quickly turned to contemplating Marie's future and how their future is tied to hers:

> *Well my career is closer, I can see the end rather than the beginning stage. I don't know where Marie's going to end up. We're in (name of community) we're likely going to retire here and likely be planted here in the ground somewhere likely. Maybe. So, I guess we'll be here if Marie's here and you know we'll be helping her out as much as we can.*

Debbie Holder and other family participants also expressed hope and optimism for Debbie's ongoing recovery as reiterated by Trudy:

> *I feel that if Debbie has peaked for her physical and mental healing, I think it's wonderful for her to have the life she has now. I think she's going to slowly get better, like just as time goes on because I can still see the progress. It's a good feeling to know that there's so many supports around for all of us. Like for Debbie, but we're all here for each other as well.*

For Margaret and Frank Mercer, the future is about planning for ongoing generational responsibilities of care.

> *We do have a document through the lawyer, and in the document indicating that if something happened, her brother is lined up there to take care of them. It's hard to think of it for him too because he's got little children that he obviously feels very responsible for and committed to. And, I think he's mulling it over and find out how this will work for him or how he's going to make it work for, when the time comes… Well, future, Melanie will always need some assistance with living. The children are already getting a sense that they will hold the unit together and be with their parents and things like that. So, the future, it'll still go on. Family look after family and this is family.*

The Holder family participants relayed the fear of future brain injury, best summarized by Brent.

> *So, I think where that's coming from for me is that there were many times she wasn't the Terri to be around that we fell in love with and all that. And I mean I don't want her to go back there. I'm just more mindful of that kind of stuff.*

The Cross family hope for Evelyn's continued recovery so she can *"find her happy place again*." Greg raised a future worry different from other family unit participants; as caregiver what if he gets sick? In Greg's thoughts about the future he considers the impact of future health issues on their marital relationship.

> *There's my question for the evening. As a caregiver, you're somebody who gives a lot and then you say, well what happens to me? So, if two people that are together in a relationship who talk 24/7 about it, and are together as soulmates, and then the other person, the caregiver becomes ill or something and not able to deal with things, that's more than just anybody else entering into it.*

These findings suggest living with ABI is an undertaking that extends into the future, continuing to impact these families as they try to anticipate the unknown.

Summary

In this chapter the master narrative theme findings of this study were presented. Six separate family units participated in this study. Their stories engendered rich and meaningful data. The master narrative themes were derived from identifying common elements across family unit participants and were structured to replicate the chronological boundaries of the three-life stage chapters of the narrative interview process: chapter one - family life before the ABI event, chapter two now – living with ABI, and chapter three - future family life. Participants' stories reflect an odyssey that remains incomplete. The themes presented illustrate ABIs are life changing events that dramatically impact individuals and family members as they experience loss and unknown futures. Yet these themes signify families are strong and resilient. They are able to build capacity and remain firmly grounded in the belief and value of being a family.

Chapter Five: Discussion

Known as the ‘silent epidemic’, the affects of ABI on individuals and families are experienced worldwide. Located in a midwestern province of Canada, the purpose of this study was to investigate families’ perspectives of the impact of an ABI event. Specific objectives included: 1) to understand families’ experiences with ABI; 2) to explore the impact of ABI on families’ attitudes, beliefs and identity; and 3) to gain greater understanding of families’ relational experiences to each other, their community and health practitioners for the purpose of supporting a family-centered model of care. The purpose and objectives were addressed through the employment of: 1) the family is who they believe themselves to be “a self-defined group of individuals” (Eggenberger & Nelms, 2007, p.284); 2) the definition of family research allowing for the individual and family system to be studied together (Robinson, 1995); and 3) narrative inquiry methodology: in the context of life-story research, utilizing the models of narrative analysis by Lieblich et al. (1998) and Riessman (2008). The intersection of these three research design methods is distinctive, uniquely positioning the study findings to contribute to additional understandings of the impact of ABI on families.

In this chapter, both reflections from this study and the findings of this study, will be discussed. To begin, reflections on the methodology of narrative inquiry and family research are presented. Secondly, study findings are considered within current empirical literature on ABI and loss, followed by reflections on key findings. Next, study findings situated within ambiguous loss theory are discussed. Finally, implications for health care practice and research are discussed and conclusions are drawn.

Reflections on Narrative Inquiry Methodology and Model of Analysis

This is the first known study to incorporate narrative inquiry with family research. Narrative inquiry was chosen as the most appropriate methodological approach for this research study based on the purpose of the research, the research question, philosophical underpinnings and theoretical framework of the study. After conducting the research, it is apparent this methodology can make a positive contribution to family research. A strength of narrative inquiry was the ability to explicate the characteristics of temporality, relatedness, meaning, and identity. These characteristics resonated throughout the study findings. Temporality, was affixed to the families' narratives in their lives before the ABI, now living with the ABI, and the potential future of living with the ABI. Relatedness was manifested by the families' acute sense of belonging to each other, which further adhered them to their identity as a 'family'. These families' beliefs revealed the ways in which they interpreted their world in living with ABI and how they built shared meaning which strengthened their value of family.

The a priori determined life chapters helped in making narrative development less awkward. By guiding the timeline for families, it gave them a place from which to start their narratives avoiding temporal confusions and misunderstandings, and assisted in the time management for each family interview. Using pre-set life chapters, however, can create a perception of power imbalance between the participant and the researcher. Co-creating a life history grid allows the participant to choose their own chapters and titles which can assist in building a level of expectation for detailed accounts (Riessman, 2008). The advisability of using a priori chapters or having participants determine their chapters may hinge on the amount of data a researcher may want to collect. The open-ended style of narrative inquiry interviewing allowed for families to describe and define what was important in their lives; generating detailed accounts and obtaining rich data (Lieblich et al., 1998; Riessman, 2008).

Incorporating the model of data analysis by Lieblich et al. 1998, into family research was considered unique. Overall, this model was deemed an appropriate fit with transactional level data collection. The holistic-content and holistic-form modes of analysis proved effective in identifying global impressions and themes. The categorical-form cell dimension helped to identify the emotional content and include it within the global impressions. Narrative researchers acknowledge words are only one form of communication. Other forms, such as sounds, gestures, images, and body movements are integral to communicating meaning (Riessman, 2008). Therefore, a limitation of Lieblich et al's (1998) model was the lack of a cell dimension to analyze participant movements, bodily actions and gestures. As visual narrative analysis models such as photo voice have rapidly developed (Riessman, 2008), it is hoped models of analysis can be further broadened to include gestures and body movements.

A constant criticism of narrative methodology is its inability to be extended to a wider population (Elliot, 2012). According to Riessman (2008), narrative inquiry can be classified as a form of case study. In situating narrative inquiry within the category of case study, Flyvbjerg's (2004) arguments that were developed to counter the generalizability criticism within the context of case studies are relevant. Flyvbjerg (2004) contends: context dependent knowledge is more valuable than predictive theories and universals; formal generalization is overvalued as generalizations can occur from a single case; and, there is no greater degree of researcher bias noted in case study analysis. Following on Flyvbjerg's (2004) conclusions it is reasonable to infer knowledge obtained from this narrative inquiry study examining families' experiences living with ABI can potentially be transferred to similar populations in other geographical locations.

Reflections on Family Research

Engaging in family research is a rewarding yet intricate and complex process. In particular, the quantity of data and the length of time for analysis and data presentation can be overwhelming at times. In hindsight, the use of video and a second person to identify patterns of communication would have added further rigour to the data collection and analysis process. For me as researcher, a significant limitation of family research was the length of time it took to complete data collection. During the data collection phase, I became aware that while individuals may have been interested in participating, either they did not want family members involved, or family did not want to be involved, or there were impediments in gathering family together for an interview. My recommendations for researchers interested in doing family research is recruit widely and include longer recruitment time frames.

Study Findings Situated within Current Literature on ABI and Loss

As previously identified in Chapter Two, the majority of scholarship on ABI and loss has been obtained from *family-related* research in which individual family members described their own experiences or presented their views of the “family perspective”. While the emphasis for this study was exploring the ‘holistic’ perspectives of families living with ABI, several of the study findings are consistent with the literature in which individuals presented their views on the “family perspective”. This section discusses the study findings situated within the literature on individual family members’ perspectives of the impact of ABI. To begin, the findings from the perspectives of the individuals with the brain injury are discussed; followed by a discussion of the study findings situated within literature on ABI and the role of the primary family member or caregiver, children and siblings, and the marital system.

Brain injured individuals' perspectives. Overall, the study findings remain consistent with the literature on the individual, ABI and loss. In this study, all six individuals who had the brain injury described degrees of cognitive, physical and emotional impairments. Living with these impairments made them different than before the ABI as they talked about how experiencing these difficulties impacted on their identity, employment, independence, quality of relationships, leisure activities, and emotional health: all valued areas of their life. These findings support descriptions in the literature that loss of capacity including physical, cognitive and emotional functioning are at the center of loss for those who have had an ABI (Fraas & Calvert, 2009; Jones etal., 2011; Jumisko et al., 2009; Murray, 2001; Nochi, 1997; Roundhill et al.,2007). The findings from this study on the effects of loss of employment and independence as quality of life issues are supported in the literature (Dijkers, 2004). In particular, study findings are in accord with current knowledge of individuals' experiences of loss and self identity as a *"change in sense of self"* as defined by Thomas, Levack, & Taylor (2014):

> A change in one's inner subjective experience as a result of changes in egocentric or sociocentric aspects of self, or in the relationship with one's identity as shared with others. These changes are of sufficient magnitude that a process of evaluation, acceptance, and adaptation is required to regain a unified sense of self. (p. 1043)

Even though individuals in this study had varying degrees of severity of brain injury and were in different stages of their recovery process, findings from this study suggest changes in the sense of self occurred throughout the spectrum of injury severity (Bryson-Campbell et al., 2013; Inkmann, 2001; Jumisko, et al., 2009). Family member participants identified with the ABI described differing pre and post self images (Nochi, 1998; a; 1998; b; 2000; Nochi, 2010), loss of identity impacting on their emotional well being (Vickery et al., 2005), and dealing with long term memory issues by piecing together stories about themselves from interaction with others (Nochi, 1997). The participants in this study also reported using social contexts and acquiring meaning to help them rebalance themselves, as noted in Gracey et al. (2008).

In this study, five participants with the ABI were women; which is interesting, considering it has been reported males have a greater incidence of ABI (Gelech et al., 2019; Howes et al., 2005). Also intriguing, was three of the five women with ABI were the impetus in organizing family members' participation. In considering gender, this raises an interesting question: Are women more willing to participate in ABI family research? Furthermore, an increasing amount of *family-related* literature is focused on women, recognizing sex and gender influence women's experiences of living with ABI. To date this literature is suggesting women are continuing to struggle with positive body image, healthy relationships, self-esteem (Gelech et al., 2019); depression and hope (Oyesanya & Ward, 2016); and domestic gender roles (Haag et al., 2016). In the present study, women participants with the ABI described maintaining a nurturer role; whether this entailed caregiving for parents with ill health or generally worrying and monitoring the health and well being of all family members. For these women, the act of nurturing appeared to be affixed to their identity; a role not easily relinquished. In contrast, the men of this study who were in the caregiving role appeared able to institute 'time outs' from caregiving that were supported by family members. These findings suggest the social construct of gender contributes to women's differing experiences of living with ABI (Haag et al., 2016). Considering the findings from this study point to the significance of relationships and family cohesiveness, domestic gender roles may have had an impact on shaping the master thematic findings of this study.

Overall, in the empirical literature on the individual, ABI and loss remains focused on individuals' perceptions of their bio-psycho-social world. An important consideration not highlighted in the current literature are the findings resulting from participants describing their experiences of having an ABI within the family unit. During the interviews, as participants were describing what it was like to have an ABI, their family members demonstrated listening and understanding by communicating empathy and providing affirming positive supportive comments. In turn, after hearing family responses, the individuals reciprocated with acknowledging family support and its importance to their recovery. These findings address the significance of relationships and connections between family members and how they have the potential to influence perceptions and individual quality of life outcomes.

Caregiver perspectives. The *family-related* literature on ABI and the role of primary family member or caregiver are discernable in the study findings. In this study it was novel to find mainly men in the role of caregiver, differing from previous literature suggesting women are more often in this role (Savage & Egan, 2018; Zeigler, 1999). In the literature on ABI and caregiving, even though descriptions of participants are categorized by gender, often the findings are presented as a totality of participants' responses. As there appears to be a dearth of literature with men in the caregiving role living with ABI, there is potential for further exploration. Within the identified roles of husband, spouse, and parent(s) family member participants in this study assumed caregiver responsibilities (Gan et al., 2006; Livingston et al., 2010), 'taking on' most of the direct physical, emotional, and instrumental assistance to the brain injured member (Allen et al., 1994). Study findings are also congruent with the literature noting differences between primary and secondary caregivers (D'Ippolito et al., 2018). In this study there were distinctions between those carers who spent the most time with the ABI member and made the majority of the day -to -day decisions, and family members who provided additional support. In this study, several adult child participants provided additional caregiver support. Also, findings from this study suggesting family members in the primary caregiving role experience stress and burden is in accordance with the literature (Piyakong, 2014). Study findings are also suggestive of positive caregiving experiences correlated with high levels of family support and functioning (Hanks, et al., 2007). However, in this study there was no evidence to suggest distinct differences in levels of stress, grief and burden between parental or spousal caregivers as noted in the literature (Kratz et al., 2017; Kreutzer, et al., 1994). As well, in this study, family members in the role of carers expressed concerns about the care provided in the health care system, indicating study findings are in accord with the research stating caregivers are not satisfied with health care service transitions, the fragmentation of services and the lack of community-based supports (Piccenna et al., 2016).

Perspectives of children and siblings. The *family-related* studies reviewed regarding the impact of ABI on children have concentrated on children under the age of 18. Adult children and siblings as family members did participate in this study, and the findings suggest these family members did experience degrees of psychological impact as a result of the ABI event. As the age requirement for this study was limited to age 18 and older, other family members gave voice to the children who could not participate. These family members talked about the children expressing anger, sadness, embarrassment, and confusion as they experienced a parent who had changed since the ABI event. These findings are reflective of the research indicating children experience loss, grief and emotional distress (Butera-Prinzi & Perlesz 2004).

Marital perspective. Of the six family units participating, three families included marital relationships in which one partner was impacted by an ABI event. While the partners reported taking on a caregiving role while remaining together as a marital unit, the findings from this study did not reveal specific evidence to make any other interpretations regarding the impact of ABI on marital stability or quality. Considering this finding, a conjecture can be posited about the comfort and boundary levels of the participants in this study to discuss their marital dynamics in front of other family members.

The findings in this study support the *family-related* literature in recognizing families are also impacted by brain injuries and once they occurred, were something which “continued to permeate their lives, to the very core, and remained the single most significant characteristic of their existence by which they defined all future life experiences” (Leith et al., 2004, p. 1204). Also, the findings of this study reinforce the knowledge neurobehavioural sequelae are challenging for families, as they were ‘hidden’ from view (residing internal to the individual) making families’ experiences of loss distinctly different as the affected family member is not the same person (Webster et al., 1999). Overall, findings of this study reflect the current insights on how ABI affects various parts of a family system; providing individual perspectives on the family. The next section will identify what was learned from family research with the individual and the family system.

Reflections on Key Findings

The cornerstone of this study was *family* research meaning family as a group was the unit of analysis. Therefore, transactional level data generated through discernable interactions amongst multiple family members was collected for this study. Transactional level data allowed the interrelatedness amongst the families to be elevated to the foreground signifying the findings are a product of the system different from the sum of its parts (Fisher et al., 1985). Therefore, the findings are representative of a ‘holistic’ perspective. Two key findings in this study; 1) family adaptive capacities; and 2) experiences with the health care system need further attention in their significance to advancing knowledge and understanding on ABI and families.

Predominantly, the literature has consistently reported ramifications of ABI on families as negative; with prolonged exposure to stress and strain and harmful effects on families' social, emotional, structural, and financial functioning; role changes; and challenges to core values and resources in families (Brooks, 1991; Christensen et al.,1997; Degeneffe, 2001; Dell Orto, & Power, 2000; Florian, Katz, & Lahav, 1989; Kosciulek & Lustig, 1999; Lezak, 1988; Mauss-Clum, & Ryan, 1981; Townsend & Norman, 2018; Webster et al., 1999). Rather, the findings of this study offer a counterbalance to these bleak reports.

Embedded in family systems theory is the notion that families are engaged in dynamic processes that over time allows them to find numerous ways of coping and adapting (Walsh, 1996, 2012). As the theory and science of family systems evolved, families were no longer viewed from a deficit pathological model perspective (Gottlieb, 2013; Hawley & DeHaan, 1996; Walsh 1996, 2012). Instead a strengths- based perspective arose, assuming families, when dealing with family stresses and challenges had their own resources and strengths that allowed them to resolve their difficulties (Black & Lobo, 2008; Gottlieb, 2013; Hawley & DeHaan, 1996). Accompanying this focus on family strengths was the emphasis on family resilience (Hawley & DeHaan, 1996). Family resilience research recognizes the importance of the identification of protective mechanisms families use to mediate the relationship between their exposure to stress events and successful adaptation and competence (Patterson, 2002). These family protective factors have been mainly categorized under the domains of: belief systems; cohesion; flexibility; communication/problem solving; and, resources. Belief systems are considered protective if families are able to develop meaningful perspectives about the adversity (Walsh, 2002, 2003). Olson & Gorall (2003) defined cohesion "as the emotional bonding that couples and family members have toward one another" (p. 516). Families that are connected are more protected than families less engaged with each other (Olson & Gorall, 2003). Families demonstrating a stronger ability to be flexible when handling disruption, change and stability are considered to be demonstrating resilience (Olson & Gorall, 2003; Walsh 2002, 2003). Clear communication, use of positive problem-solving strategies, and families' abilities to utilize resources are also considered to be important factors towards demonstrating family resilience (Benzies & Mychasiuk, 2009; Walsh, 2002, 2003).

The two key findings from this study have illuminated families' strengths and resiliency by demonstrating families have inherent competencies and adaptive capacities that help them to establish effective psychosocial coping and functioning while living with ABI. Instead of families experiencing increasing loss of identity issues (Landau & Hissett, 2008), in this study, families' beliefs about their identity as a family unit were maintained and became more solidified while living with the ABI. These families described an increased sense of belonging and used their relationships as resources for each other; thereby having less functional difficulties as noted by Segev, et. al. (2018). While families in this study described stressful and challenging experiences, the role changes they recounted were not viewed as a loss that was negative and burdensome (Whiffin et al., 2015); rather families demonstrated flexibility as they accepted the forced role changes and adapted. Establishing collective beliefs and meanings of the ABI situation helped these families tolerate the losses and adjust to the different circumstances. As one participating family self identified as aboriginal, cultural values could have been a factor in some of the families' collective beliefs about loss. However, I did not find any evidence of specific cultural influences in my data analysis. Participant families' demonstrations of strength and resiliency attest to their capabilities as carers and supporters of their loved ones with ABI.

In taking over the caregiving responsibilities for the members with the ABI, participating families in this study encountered issues with the health care system. Family members spoke about the decrease in resource availability following acute care. Their experiences with the health care system are affiliated with the literature reporting on unmet service and support needs throughout the continuum of care from hospital to home (Degeneffe &Bursall, 2015; Kirk et al., 2014; Lefebvre & Levert, 2012; Murray et al., 2006). In addition, findings from this study highlight families do not consider themselves to be in collaborative relationships with health care professionals. Compounding lack of collaborative relationships with the premise families do not always know what they should ask for or expect (Denham et al., 2016), suggests the health care system is continuing to restrict involvement of the families in the planning, delivery and evaluation of care (Levack et al., 2009; Miller, 2012). At the same time research has identified families want to be involved in all aspects of care (Fleming et al., 2012; Stejskal, 2012). Research has also shown health care providers are often hesitant to include family members; as families are seen as barriers in the patient-health clinician relationship (Creasy et al., 2015).

The two key findings in this study; 1) family adaptive capacities; and 2) experiences with the health care system represent the ‘holistic’ perspectives of all the family unit participants in this study. These key findings elucidated families’ strengths, resiliencies and expertise in living with ABI, and also exposed relationship challenges between families and health care professionals. Knowledge translation of these findings will be discussed in the sections on implications for practice and research.

Study Findings Situated Within Ambiguous Loss Theory

It is critical to return to the theory that guided the research and contributed to the interpretation of the findings (McEwen & Wills, 2011). To ensure coherence with the study design it was important to use a theory underpinned by a systems framework (Marcellus, 2006). Therefore, the theoretical framework which underpinned this study was ambiguous loss theory.

In this study, the families' experiences of loss adhere to the definition of ambiguous loss as a unique stressor event in which a loved one is "physically present but psychologically missing as a result of some cognitive impairment or memory loss from illness, injury, addiction, or obsession" (Boss, 2016, p.270). Families' descriptions of their loved ones being 'not the same', 'different' or 'lost' substantiated the ambiguous loss definition. To varying degrees, these families continue to experience ambiguous loss because there is no resolution; as there is in a clear-cut death. This finding aligns with other research descriptions of ABI and ambiguous loss (Kean, 2010; Kreutzer, Sima, Mills, & Marwitz, Lukow 2016; Landau &Hissett, 2008).

Boss states the ambiguous loss stressor (2016): "leads to a perceptual variable called boundary ambiguity; it is defined as not knowing who is in or out of one's family system, and thus there is incongruence among individual perceptions about family membership and roles (p. 270)." My findings indicate the participating families did not experience boundary ambiguity as their pre-established family unit identity was maintained and solidified, the individual member with the ABI remained embedded within the family unit, and family members were united in role adaptations. However, some acknowledgement of boundary ambiguity was noted as friends 'disappeared' from the family circle.

Resiliency has a specific meaning in ambiguous loss theory; which is the ability to increase one’s tolerance for ambiguity resulting from the ambiguous loss event (Boss, 2016). According to Masten (2016), common factors associated with resiliency in ambiguous loss are:

> 1) Revised attachment in the psychological family; 2) Adjusting mastery; 3) Optimism, hope, faith, coherence; 4) Flexibility, collaborative problem solving, tolerance for ambiguity; 5) Making meaning, collective meaning, coherence; 6) Reconstructed identity; 7) Reconstructed family rituals and routines; and 8) Rituals and memorial ceremonies (p. 290).

My findings suggest families were able to accept, tolerate and live with the ABI situation; and in doing so they demonstrated flexibility in role adaptations and collaborative problem solving. Families in this study also established collective belief systems and maintained family rituals and routines. While the individuals with the ABI were processing changes to their identities, the families’ identity as a grounding stable force was solidified rather than reconstructed.

Although Boss (2006) recognizes families are equipped with internal coping, adaptation and resilience factors, a significant part of ambiguous loss theory attends to treatment strategies for the purpose of promoting resiliency. Therefore, it is less clear whether inherent strengths and capacities of families are considered and appreciated prior to implementing a plan for treatment, or just subsumed within the resiliency definition. Although my findings have shown degrees of variation in the concepts of boundary ambiguity and resiliency, ambiguous loss theory was a suitable fit for the study as it reinforced the existence of ambiguous loss as a phenomenon for families living with ABI; further adding to understanding of families’ experiences and their relational experiences to each other.

Reflections on Study Implications for Practice and Research

My findings suggest minimal supports exist for families impacted by ABI and health care professionals need to acknowledge and attend to the entire family system and not just the individual and primary care giver. In particular, the two key findings related to family adaptive capacities and experiences with the health care system, highlight the need for health care practitioners to continue to adopt practices informed by frameworks espousing strengths-based care and family centered care. The prominence of the medical model has created a health care system focused on a systematic approach to diagnosis and treatment; reducing people's identities to a disease process, thereby distancing the relationships between individuals, families and health care professionals (Gottlieb, 2013). The foundation of strengths-based care is the focus on persons' and families' strengths in order to promote care that empowers persons and families to take control of their own health and healing (Gottlieb, 2013). Based on the factors of respect, information sharing, participation and collaboration (Miller, 2012), the essential ingredients of the family centered care model are collaboration and partnership with the entire family for the purpose of planning, delivery and evaluation of health care (Creasy et al., 2015). Both of these frameworks share:

> A shift in focus from a disease model to a process model of {persons and families} living with an illness or condition. A shift in focus from the practitioner and organization to the person and {family}. A rebalance in the power between practitioners and persons. Recognition that the person {and family}, not the practitioner, is ultimately responsible for his {their} own health (Gottlieb, 2013, p.21).

Both of these frameworks have been absorbed into the model of family nursing. For a number of years, the discipline of nursing has advanced family focused nursing care through developing models of family assessment and intervention (Wright & Leahey, 2009) and emphasizing the attitude of *thinking family* and linking it to intentional actions geared towards building relationships and partnerships between nurses and families (Denham, Eggenberger, Young, & Krumwiede, 2016). For health care practitioners working with ABI individuals and families, the first practice step is to purposefully 'THINK FAMILY' and then adopt intentional actions of knowing families' strengths and capabilities to collaborate with them throughout the stages of recovery and living with ABI (Denham et al., 2016). Health care professionals are more effective collaborators when they generate greater understandings of family needs. Gaining knowledge about: the person in the family who has the greatest influence on member health; family expectations; family decision making dynamics; and individual and family perspectives helps build effective partnerships and communication (Denham et al., 2016). As with client-centered practice, the linkage between family centered care and improved individual and family health outcomes is supported by the evidence (Christian, 2018; Wright et al., 2016). Additionally, ambiguous loss theory with its intervention strategies can provide direction for tailored treatment implementation.

The study findings highlight the need for ongoing family research as these findings have only touched the surface of what can be learned from families who are coping with living with ABI. This study has exposed the need to continue researching the development of family centered care frameworks which recent articles within the ABI and loss literature have started (Creasy et al., 2015; Fisher, Bellon, Lawn, Lennon, & Sohlberg, 2017). These findings when viewed through the paradigm of strengths-based care offers an alternative from preoccupation with what is going wrong and needs fixing, to focusing on positives and what is going well (Gottlieb, 2013). A systematic review on strengths-based approaches working with families affected by progressive neurological illness revealed there is little evidence of the use of strengths-based approaches with this population (Tams, Prangnell, & Daisley, 2016). To date, there is also minimal evidence of the strengths-based paradigm being considered in conjunction with ABI and families, theoretical or otherwise.

The theoretical frameworks of ambiguous loss theory, strengths-based care and family centred care are emerging as major paradigms to guide health research and practice with families living with ABI. Commencing with the recognition of the phenomenon of ambiguous loss, together these frameworks acknowledge individuals and families have strengths and capabilities to influence and direct their own health care needs; thereby placing greater emphasis on collaborative partnerships between individuals, families and health professionals in the planning, delivery and evaluation of care (Creasey et al., 2015; Gottlieb, 2013). Engaging in a health professional practice informed by these major paradigms and theory is an iterative integrative process also involving education and policy development. Health educational systems need to be advancing these frameworks within their undergraduate and graduate curriculums and governments need to be developing family first policies which define family widely and inclusively, and require a spectrum of services over a broad period of time.

Conclusions

The exploration of families' experiences living with acquired brain injury affirmed impacts of ABI are relational, and revealed while families contend with ambiguous loss they have capacities and competencies to affect their own healing processes. Through this study, it became apparent living with ABI is a life-living process-an odyssey underscored by the need for health care systems to incorporate relational thinking and practices that focus on getting to know families and collaborating with them on any potential needs and or supports. This study, by illuminating *the individual and family together* can facilitate further development and implementation of family research across multiple health issues.

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Appendix A

Interpretive Family Synopses

The Carter Family: Global Impression

This all male family's narrative evokes a strong sense of commitment to rebuilding hope and healing from scarred and broken connections. Led by the younger brother, they recount a story of reconciliation. The global impression is one of connections, missing connections, and reconnections. Theirs is an emotional narrative as expressed by the participants. For this family, the father's ABI event is thought to be a blessing, a means of re-connecting father and sons. However, opportunities for reconnecting are being missed as those members who have different thoughts and perceptions remain on the periphery of this male family unit.

Participants in this all male family unit were: father Allen; older son David, and the younger son Jeff. The family interview took place in Jeff's home at the kitchen table, and once I arrived Jeff's wife and children left the home for the 1.5 hours duration of this interview. Allen had initiated the interview and asked his sons to participate, which they agreed.

The plot unfolded led by Jeff. Their narrative developed from adversity and ascends to healing and reconciliation. Jeff begins by saying. *"I'll start us off then…my parents are separated."* The first two segments of the global impression, connection and missing connections occurs early in this narrative. Family life prior to the ABI revolved around the children maintaining connections to Allen who, due to his job, was often away from home. During the martial breakdown some realignment of family connections occurred.

However, it is the catalyst of the ABI event that shifts their narrative from adversity to one of hope for emotional healing, reconnecting, and reconciliation. Allen's ABI event occurred when he was living in another province and away from his children. Allen's retelling of his ABI event and the subsequent consequences to his life appeared to be an important piece of the reconnecting process between father and sons; as Allen wanted his sons to understand what he went through and the resulting changes for himself. Again, as told by Jeff:

> *This was kind of a blessing for our family We're more understanding of each other. It kind of fast tracked us to where we are right now. Where we do stuff for each other and we want to do things with each other*.

The retelling of their earlier family life elicited displays of strong emotions as all three of them were tearful at several times thorough out the interview (at one-point Jeff got up from the kitchen table and retrieved a box of Kleenex and brought it back for them to use), especially for David as he appeared to be the most emotionally affected and speaking was difficult. David acknowledged: *"Just going back on thinking about it all…still quite painful."* Even though aspects of the Carter Family's story were painful essentially the global impression is one of the fluidity of connections. Recognizing the complexity of connections and relationships this family has demonstrated their strength in reclaiming meaning of family and building a family identity which holds the three of them and their spouses and children together as a family unit. Jeff concluded their story by stating: *"I think we all have changes no matter what…family means a lot that we make adjustments to continue what we have and make sure that we're all included."*

The Cross Family: Global Impression

This blended family's narrative evokes a sense of lives being brought together and learning to live as a new family unit yet members continuing to maintain their own individuality and separateness. With the advent of the ABI, this family has again come together to accommodate and support through the sharing of roles.

This family came together 11 years ago as a result of the marriage between Evelyn and Greg. Joining the family at that time was Evelyn's two children Shelley and Curtis. Ellen was born 10 years ago. Ellen because of her age could not participate in the interview. Although she was seated in the kitchen area doing homework with ear phones on, a couple of times her voice was heard jumping in to add something to the conversation.

Shelley's words helped to provide the impression of their experience of being a blended family; separate yet together.

> *We also would do family camping trips. Not necessarily always all of us together. Sometimes it would be mom and Greg with Curtis or mom and Greg with me or sometimes separately but camping trips has definitely come up quite a bit. And Curtis and I had lived here in or out both of us at different times. But never all of us under the same roof in a long time at this point... But then a typical day seems like everybody had their own isolated agenda or something that they're getting towards. Everybody has a different schedule. And you're all trying to interact and go through.*

However, since the ABI, this family has minimized their level of independence and come together to share in the responsibilities of caring. While Greg has become the main caregiver, Shelley and Curtis share in this role resulting in increased communication and contact. *"Since then, I would say that my brother and I are much more communication and contact. We're all very* *independent beforehand… We've been trying to chip in as much as we can. Greg's obviously taken on 98% of it. But we try to do what we can. Everyone has to adapt and hopefully mom pulls through."* Together they all are, including Ellen, learning how *"to relate and react to the brain injury."*

The Holder Family: Global Impression

The Holder family narrative evokes the sense of lives committed to the ministering of others. Terri and Brent (wife and husband) while raising a family of two children worked in demanding and consuming professions. Both worked in the church ministry; Terri as a congregational Minister and Brent as a prison Chaplin. However, since the arrival of the ABI event this family is in the position of being ministered too, as friends and the church community have become a significant part of their support network.

Alongside the biological family participants, Terri, Brent, son Matt, this family also invited two family friends to participate; Mona and Macey. It is the words of Mona and Macey that reveal how important Terri is to the congregational community and the tremendous impact and influence both she and Brent have in their roles.

> *We hired her as our minister. She was a young vibrant minister who brought tremendous gifts to our church, our congregation. And you know, it was the beginning of our very deep friendship. Brent was and still is the kind of man that young people are attracted to. I think he, by gaining their independence or letting them push those boundaries, even when their parents didn't want those boundaries to be pushed, and I think that's why they (referring to the young people) loved him so much.*

Mona and Macey's statements contribute to the impression the family identity is centered on ministering to others.

Following the ABI event, with Brent readily admitting *"It think I felt confused about it and used the opportunity to kind of work harder,"* the family experienced a lot of support that gives the impression they were being ministered to:

> *…the two of you (speaking to Mona and Macey) you spent a lot of time with her drinking tea and being a gentle presence as well, right? We had a lot of people. I had a lot of people touching base with me. But because we've lived in the same circle, vis-à-vis the church, right, and so they know both of us. And the support I got, I had two colleagues, one who I didn't know very well, would take me out for lunch to check in to see how I was going. It was very helpful.*

Through these acts of ministering the overall impression I was left with was the creation of a strong and secure safety net which will carry this family and their community forward into the future.

The Mercer Family: Global Impression

The Mercer family narrative lends itself more to the global impression of the qualities of family solidarity, strength and resiliency. Their narrative unfolded through full descriptions of their family life. Their accounts engendered images of a busy active family who self-identify as Aboriginal. Professional career parents raising their two children; involved in living in their community, playing sports, and taking many family vacations to visit family in other parts of the province. Their narrative took them through a family life cycle of children growing up, moving away and the birth of their first grandchild. Sad times including family deaths and significant health concerns were also revealed; all the while weaving a tale of family as: *"community sharing knowledge and experience; teachers; presence; and healers."*

Their narrative was told sitting around the family kitchen with Frank (father), Margaret (mother) and Melanie (daughter with ABI). Melanie's two children April and Brian could not participate as they were not adults. However, Brian could be heard playing guitar, and on several occasions, he came through the kitchen to which Frank commented; *"he is listening, learning, and paying attention."* Melanie's contribution to their narrative included responses that were repeated and given without inhibition as she would interrupt on occasion and retell her story of how embarrassed her children were when she walked into a male washroom. During these moments, Frank and Margaret sat quietly making no response, until Melanie had finished, and then they would continue with their narratives as if no interruption had occurred. Their patient and calm demeanour was interpreted as a sign of acceptance of her cognitive challenges, as there were earlier years when Melanie's repeated communications would cause angry frustrated responses from family members; now they know the *"question can be asked many times and you just answer it."* I observed Frank and Margaret also lived with the Melanie who could respond appropriately to the look of pain on her mother's face and ask if she needed her legs lifted, and make more tea when “our cups were empty.”

The Mercer family defined themselves as *“closer”* and *“never far from each other.”* I interpreted their response as evidence of their solidarity, strength and resiliency in understanding and accepting of the ambiguity that is a part of their experience living with an ABI.

The Stetler Family: Global Impression

The Stetler family narrative lends itself to the formation of two main global impressions. The first being the recognition of just how powerful and traumatic the ABI event was for this family, and secondly how it has been the women of this family that have guided and nurtured the value of caring.

Debbie Stetler (family member with the ABI) chose the family members that she wanted to have participate in the family interview. Therefore, those who sat around the home dinning room table included: Mike (husband); Rob (younger son); Colleen (step-daughter); and Trudy (Debbie's sister).

The story of the ABI event was significant for this family. It was as if they were reliving the event as they told their story. As they began to recount the day it happened, several family members became emotional and a box of Kleenex was passed around the table. The ABI event occurred early evening and led to 911 being called and once Debbie was brought to hospital the family was faced with the words of the surgeon, *"If we operate two things can happen…she could be paralyzed or be a vegetable."* Debbie explained her tears:

> *Guess it was just such a traumatic experience for everybody. I remember the look on everybody's face. The pain I felt inside just looking at their looks on their faces. Nobody wants to see pain in their children's face and that's what I see. That's what goes through my head when I bring this all up again.*

Trudy stated:

> *But if it happened to her, it happened to us. It affects the whole family. And she was so close to dying and all those thoughts go through your head about what am I going to do*

> *without my sister? What am I going to do without my mom? And then you're so thankful when, when she survived….*

For Rob seeing his mom unconscious brought up another traumatic memory that of the death of his father from a heart attack; "*I gave him CPR in the driveway. He died in my arms. And this was just a repeat of it but she came out."*

Another key element in this family's narrative is 'caring'. This narrative is led by the women in this family, in particular, Debbie and Trudy. As stated by Trudy:

> *I think as a family, we each kind of live our own lives. We don't interfere in anybody else's lives. We're there for support. Probably the biggest bond Debbie and I have is the care of our mom. I think too, most of us, it's very important for us to get together as a family say for Christmas, Thanksgiving, Easter, that kind of stuff… I'm trying to keep the family together as much as I can and I think my sister is trying to do the same thing. And I think Colleen also appreciates, well we all do, the value of family.*

In this family caring is important and means being genuine, *"real not fake"*, and no pretense or *"judging."* Debbie specifically chose the family participants based on their caring actions. *"I wanted my husband because he is with me every day…I wanted Colleen because I owe her my life…and my sister and Rob always been so supportive."*

This family has created a circle of caring solidified by the trauma of the ABI event.

Interpretive Family Synopsis: The Wilson Family

Global Impression

The Wilson family narrative evokes a strong sense of connection and stoicism, from an active busy family life working and parenting two daughters (what they called normal), to their central focus of living with the ABI event of their youngest daughter. This family was the only family unit to decide on a second interview. On both occasions the Wilson family participants included: father Mitchell; mother May; eldest daughter Ann; and youngest daughter Marie.

I was struck with the family's visible display of connections to each other. Sitting around the dining room table they conversed freely and easily with each other often using humor to display emotional connections. At one-point Ann complimented her parents for having a *"good upbringing."* Following this remark, I observed Dad pulling out $20.00 and pretending to give it to Ann. Their display of connection also extended to the family pet dog Tradder (also a pseudonym). Tradder not only greeted me on both occasions when I entered the family home, he was allowed to join us for both interviews remaining underneath the dining room table chewing on a 'treat'. In particular, I observed the special bond between Tradder and Marie as she was consistently picking him up and talking to him.

The impression of stoicism comes from the family's mottos of *"just do it"* and *"one day at a time."* In their narratives, these phrases were stated at least 13 times by different family members. These mottos have helped the family cope through difficult stressful life events, (i.e. caregiving of elderly parents, and Marie's brain injury) as they *"didn't have time to go wallow."*

A prominent figure in the impression of family stoicism is May Wilson. May's stoic attitude is thought of as a strength by other family members. Daughter Ann declared:

> *My mom was the strong one out of everybody, she presented really well. She probably hid some of the stress stuff. She probably didn't want everybody to know what was going on…I think if you keep going and you keep your mind busy and you keep going, sometimes you don't have time to stop and reflect on stuff so you don't let it get to you.*

May herself disclosed the level to which she would maintain her stoic appearance. *"There were times I wanted to lose it and cry…I just didn't do it in front of you guys…just cry a little bit by myself."*

May's disclosure yields an inkling that sharing vulnerabilities may not be a part of this family's identity or relational dynamics, rather they appear more comfortable showing their 'funny side' alongside the face of stoicism.

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Appendix B

Interview Informed Consent for Family Member Participants

Research Project Title: Families' Experiences Living with Acquired Brain Injury: A Narrative Inquiry Study

Researcher Contact Information:

Primary Researcher:

Jane Karpa RPN, MMFT, PhD (c)

Applied Health Sciences Program

Faculty of Graduate Studies University of Manitoba

email: umkarpaj@myumanitoba.ca

phone: [redacted]

Research Supervisor:

Wanda Chernomas, RN, PhD

College of Nursing, Rady Faculty of Health Sciences, University of Manitoba

email: Wanda.Chernomas@umanitoba.ca

phone: [redacted]

The principal investigator (Jane Karpa) is a doctoral student in the Ph.D. Applied Health Sciences program at the University of Manitoba. This study is being conducted by the principal investigator in partial fulfillment of the degree requirements for a Doctor of Philosophy degree. Her research supervisor is Dr. Wanda Chernomas, and her committee members are Dr. Kerstin Roger and Dr. Tuula Heinonen.

Sponsor: The primary researcher has received funding from the College of Nursing Endowment Fund Graduate Student Research Grant and the Fort Garry Legion Poppy Trust Fund Grant.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Research Purpose

You are being asked to participate in a research study. The purpose of this study is to understand what it is like for a family living with acquired brain injury. The researchers would like to learn about this process through listening to family members coming together to share their stories about their experiences.

Who can participate?

- Individual with a medical diagnosis acquired brain injury (ABI) not associated with a progressive neurological disorder like Alzheimer's or other forms of dementia
- For the individual with the ABI, the individual needs to be living in the community, a minimum of two years after the initial brain injury event, and medically stable
- Family participants can include: persons who support, share a history and a future, and are committed and caring towards each other. Participants can include friends as well as biological and legal family member participants.
- Neither the individual member with the ABI nor the other family members need to be residing within the same household.
- All participants need to be over the age of 18, able to speak and read English, and willing to participate in a family group interview.
- Family will consist of a **maximum** of 5 self-defined family participants, per family unit, including the member with the ABI; or-a **minimum** of 3 participants for each self-defined family group, including the member with the brain injury.

What would I have to do if I agree to participate?

If you agree to participate in this study you will meet with the primary researcher (Jane Karpa) for 2 – 3 hours to share your experiences of living with ABI in a group with your family. The location for the interview will be one which is agreeable to you and the researcher, such as a private place like your home, or at a clinical or community facility. A brief break during this interview can occur if you need one. As an individual family member you will also be asked information about your demographic characteristics (such as age, occupation relationship status). With your help the primary researcher will also complete a diagram outlining other systems involved with your family. During the interview(s) Jane Karpa will be completing a form looking at your ways of communicating with each other. Following the gathering of this information you will then be asked to think about your life experiences with ABI as three life stage chapters in a book about their family. The first chapter is about your family life before the ABI event, the second chapter is now – living with ABI, and chapter three concerns your future family life. You will then be asked to talk about different family events or situations that you experienced during each of these chapters. All though the interviewer will ask you questions, it will be up to you to decide what you would like to share about your own experience. You may also refuse to answer a question if you like. This interview will be audio-recorded and then transcribed into a written document by a transcriptionist. If, following the first interview, you choose to withdraw completely from the study and ask that your responses not be considered as part of the study, the ability of the researcher to use your family group interview for data will be affected. Therefore, if this were to occur the researcher would withdraw your family from the project.

You will then be offered to participate in a second interview that can then be scheduled approximately three -four weeks following the first interview. The reason for the second interview is to allow the researcher to follow up with any other thoughts or perspectives that you would like to talk about. To help you think about any other things you would like to share about your ABI experiences, the researcher will give you, in advance, a document outlining the main points that were made in the first interview for you to review and reflect on. This second interview will be approximately 1 hr. in length, held at the same location as the first interview, and will also be audio recorded and transcribed into a written document by a transcriptionist. If you are unable to participate in the second interview you will be given the option of providing written feedback brought by another family member. If you choose to withdraw prior to the second interview and also do not want to provide written feedback, the second interview will go ahead with other family participants who choose to continue.

Are there any risks if I take part?

Similar to risks encountered in everyday life, there is a minimal risk to taking part in this study. The sharing of experiences may cause emotional responses (like crying). If you find the interview stressful or difficult, you will have a choice of taking a break, rescheduling the interview or ending your participation in the interview. If you experience intense emotional distress during or following an interview you may wish to contact your own health care provider. Also, during the signing of this consent form, the researcher will provide you with a list of resources that you may or may not choose to contact. Participation in the study involves a time commitment, and may also include potential costs associated with travel and parking.

In an interview situation you may unwittingly disclose other personal information that is not related to experiences of living with ABI. Disclosures involving child or elder abuse, suicidal or homicidal intentions may have a dramatic impact on your family members if they are hearing this information for the first time.

If this type of disclosure occurs the researcher will talk with you and the other family participants to consider not continuing and withdrawing from the study. The researcher will also inform all of you that she is required by law to report disclosures of abuse. For a report of abuse (sexual, physical, emotional) involving an individual under the age of 18, the researcher will contact Child and Family Services. For a report of elder abuse (sexual, physical, emotional and or financial) the researcher will contact the Elder Abuse Consultant for the Province of Manitoba. In the case of disclosures regarding suicidal or homicidal intent, the researcher will initiate a referral to a health care professional within the provincial mental health system.

What are the benefits?

If you choose to participate in this study there may or may not be a direct benefit to you. Some studies show that participants find sharing their thoughts and feelings helpful to themselves and the other family members, as it helps them to make sense of what they have experienced and also to feel more connected to each other. Also, study participants often feel grateful for the opportunity to contribute to knowledge development through a scientific study. You may also develop a deeper understanding of other family members' perceptions and beliefs through your involvement in this study.

Will I be paid for participating in this study?

During the signing of this consent form, you will be given $25 in cash to thank you for your time for participating in this study.

Will my records be kept private?

Only the primary researcher, the transcriptionist, and the primary researcher's supervisor will have access to the confidential information that you provide. The two other committee members, Dr. Kerstin Roger and Dr. Tuula Heinonen will not know your names and will not view the transcripts. The transcriptionist will work in a private space and/or use headphones when transcribing your recorded interview. The transcriptionist will be instructed to record only the initial of participants' first name followed by the family role identifier (i.e. S./sister; A./survivor; F./mother). Also, the transcriptionist will be instructed to not record any specific names of neighbours or health professionals. The transcriptionist will sign an Oath of Confidentiality. The faculty supervisor will have access to transcripts and will keep them in a locked filing cabinet in her office at the University of Manitoba. Your first and last name will be on the informed consent form, while first names will be on the demographic tool, and observational form. The record of your participation and other documentation will be kept confidential by storing it in a locked cupboard in the researcher's home office. The recordings of your interviews will be kept on a password-protected computer in the same office. This information will be stored for seven years after the research is completed, and then written data will be destroyed and electronically recorded data will be deleted within seven years of the completion of the research. The data will be kept for this time period in order to enable manuscript publication, presentations, and future grant applications which build upon this study.

The findings of this study will be written in the thesis and may be published in an academic journal and presentations will be given both locally and nationally. In any publications or presentations about the study findings, the researchers will aim to secure that participant identities remain confidential. Only your pseudonym will be used. Only general descriptions of identifying information will be used. Care will be taken to endeavor that any quotes used from the data to present the study findings contain no identifying information in order to protect you and your families' privacy. However, as you may have strong ties to your home communities, your family maybe identifiable to someone in the community. Therefore, the researcher cannot guarantee anonymity.

Will I be able to talk about the interview after it is finished?

At the end of the interview you will be asked how you are feeling and how you found the interview. This will give you the opportunity to talk about your feelings, thoughts, and/or concerns about the interview with the researcher immediately following the interview. As family member participants you have a responsibility to each other to maintain a level of confidentiality by not sharing explicit information about what was said during the interviews. As a family you will need to decide whether you want to tell others in your social network that you have participated in this study. If you decide to tell others about your participation you will need to limit your comments to only general information sharing.

Can I withdraw from the study?

Participation in this study is completely voluntary, and you may refuse to participate or withdraw from the study at any time, with no repercussions. To withdraw from participating in this research, you just have to let the researcher know about your decision by telephone or email. Withdrawing from the study, or declining to answer a certain question, will in no way affect your affiliation with the Manitoba Brain Injury Association or any other community service.

Who do I contact if I have questions?

If you have questions about the study, either during or after the study is completed you can contact the study investigator, Jane Karpa, on her phone ([redacted]) or by email (umkarpaj@myumanitoba.ca), or her research supervisor, Wanda Chernomas, on her phone [redacted]) or by email (Wanda.Chernomas@umanitoba.ca).

Additional Information

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

The Education and Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project you may contact any of the above-named persons, the Human Ethics Coordinator (HEC) at the University of Manitoba (474-7122). A copy of this consent form has been given to you to keep for your records and reference.

Research records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba. All records will be kept in a locked secure area and only those persons identified as requiring access to your records will have opportunity to review or copy your research records.

Signatures

Participant's Signature ____ Date ___________

Printed Name: ____

Researcher's Signature ________________________________Date _________

Would you like to receive a copy of the master narrative? ______________________________

If yes, how would you like the copy sent to you?

____

Participant signature: ____

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Appendix C

Transcriptionist Oath of Confidentiality

Research Project Title: Families Experiences Living with ABI

I, ____ affirm that I will not disclose or make known any matter or thing related to the participants that comes to my knowledge during this research project.

____________________________________ ________________

Transcriber Date

____________________________ ____________

Signature of Witness Date

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Appendix D

List of Resources

1. Participants’ health care provider
2. Klinic Community health Centre – Winnipeg
    a. Crisis line (24 hr. line) – 204.786.8686 – offers counseling service for those in crisis or to assist with problem-solving. Klinic also has counseling services including trauma specific counseling
3. WRHA Mobile Crisis 24 Hr Service - Winnipeg
    a. 204. 940. 1781- offers telephone support and crisis service including home visits
4. Interlake Eastern Region Health Authority
    a. 24 Hour Crisis Line: Provides telephone support for those in the Interlake-Eastern Regional Health Authority who are experiencing a mental health or psychosocial crisis. Also provides information and helpful resources to those who are looking for themselves or someone else.
    b. Toll Free: 1 (866) 427-8628 or (204) 482-5419
5. Prairie Mountain Region Health Authority
    a. Adult 24 hr response line for those living in the Dauphin and Roblin areas: 1-866-332-3030
    b. Adult 24 hr. response line for those living in the Brandon, Souris, Minnedosa area 1-888-379-7699
6. Provincial Crisis Resources:
    a. Manitoba Suicide Line 1-877-435-7170
    b. Klinic Crisis Line 1-888-322-3019

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Appendix E

Narrative Opportunities and Probes

First Conjoint interview with the individual who has an ABI and other family members

The initial strategy was to build rapport with the participants. The approach to obtaining narratives requires more of a conversation, a discourse between researcher and participants. Therefore, in a relaxed and unhurried manner the rapport building strategies were initiated through forms of social communication (i.e. handshakes, introductions, and getting acquainted in a settling in period). The researcher shared her professional background. The researcher also framed the interview in the context that there is no right or wrong responses as viewpoints by all participants are considered valid.

As part of the beginning strategy, it was important to set the stage for this family interview. A guiding opening statement was: "I'm interested in whom you are as a family and how you are as a family; how the acquired brain injury in one member has affected you as a family? In that regard, I'd like for you to think about your family life as three life stage chapters in a book. The first chapter is about your family life before the ABI event, the second chapter is your family life now – living with ABI and chapter three concerns your future family life.

For each of the three chapters, the first prompts were:

1. Tell me about a significant episode or memory that was a happy family time ......a difficult time or a time when you struggled as a family…and a time that was not necessarily happy or difficult but rather was unusual for how your family is together.

Followed by a question:

2. How would you describe your family during this time?

3. If I was a fly on the wall, what would I see you doing?

For chapter three, the following prompt will be asked:

4. Tell me about how you envision your family's future.

The following guide outlines questions and or prompts that may or may not be asked as the families' stories are unfolding.

5. Describe an experience of loss?
6. What is your experience of loss now and how has it impacted your family?
7. Tell me what happened.
8. How would you describe your family relationships at this time?
9. What kinds of roles were occurring in your family and who was doing them?
10. How have family members changed?
11. What else was going on during these experiences?
12. What was meaningful in your family?
13. What were your families' beliefs and attitudes?
14. How did family members demonstrate support?
15. How could family members have acted differently?
16. How do you make sense of your life?
17. Who in the family is struggling the most? And why?
18. Who in the family is doing the best? And why?
19. What are your family's strengths?
20. And the people that have been meaningful during this time?

21. What are your expectations now? For the future?

22. Hopes…….

Potential for Second conjoint family interview

If the family participants agreed to a second interview, the purpose of the second interview was to follow up with families' reflections from the first interview, clarify uncertainties and any additional perspectives/ experiences they wish to relate. To help facilitate family's reflections the researcher provided family members with points made in their first interview for them to review in advance.

The investigator would begin this second interview by asking if they have had any further thoughts about their responses. ….and if they have… Would they like to revisit any particular questions or expand on any of their previous responses?

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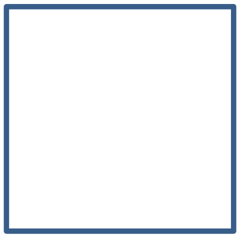
Appendix F

Genogram Tool

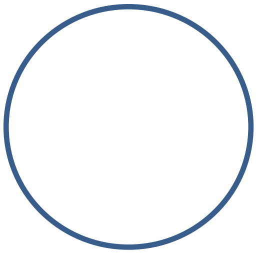
Individual demographic information and family data will be obtained in collaboration with family members and noted on the genogram.

Family genogram will be devised from the following symbols and attachment diagrams:

Male:



Female:



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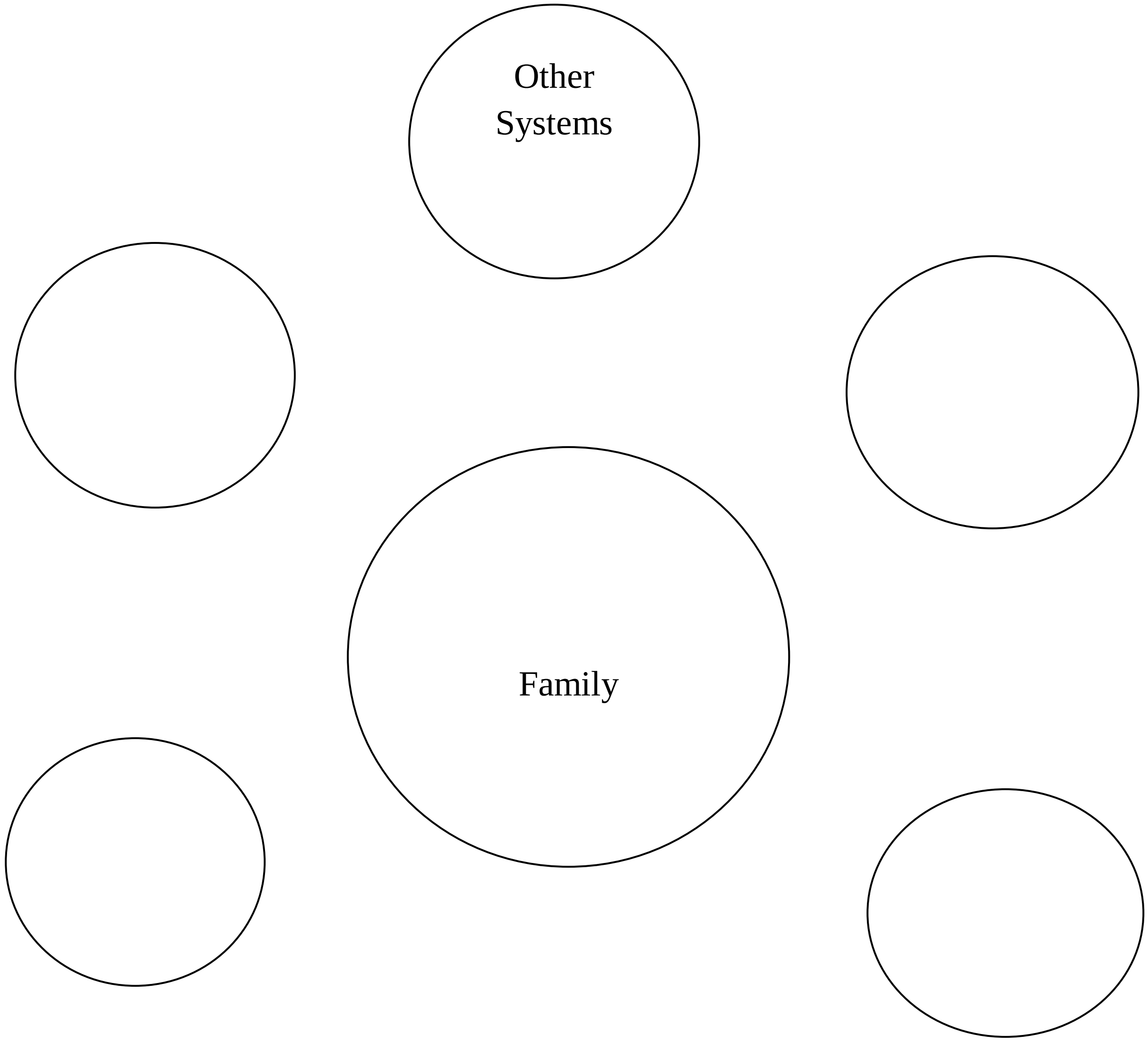
Appendix G

Eco Map

This information will be obtained in collaboration with family members.



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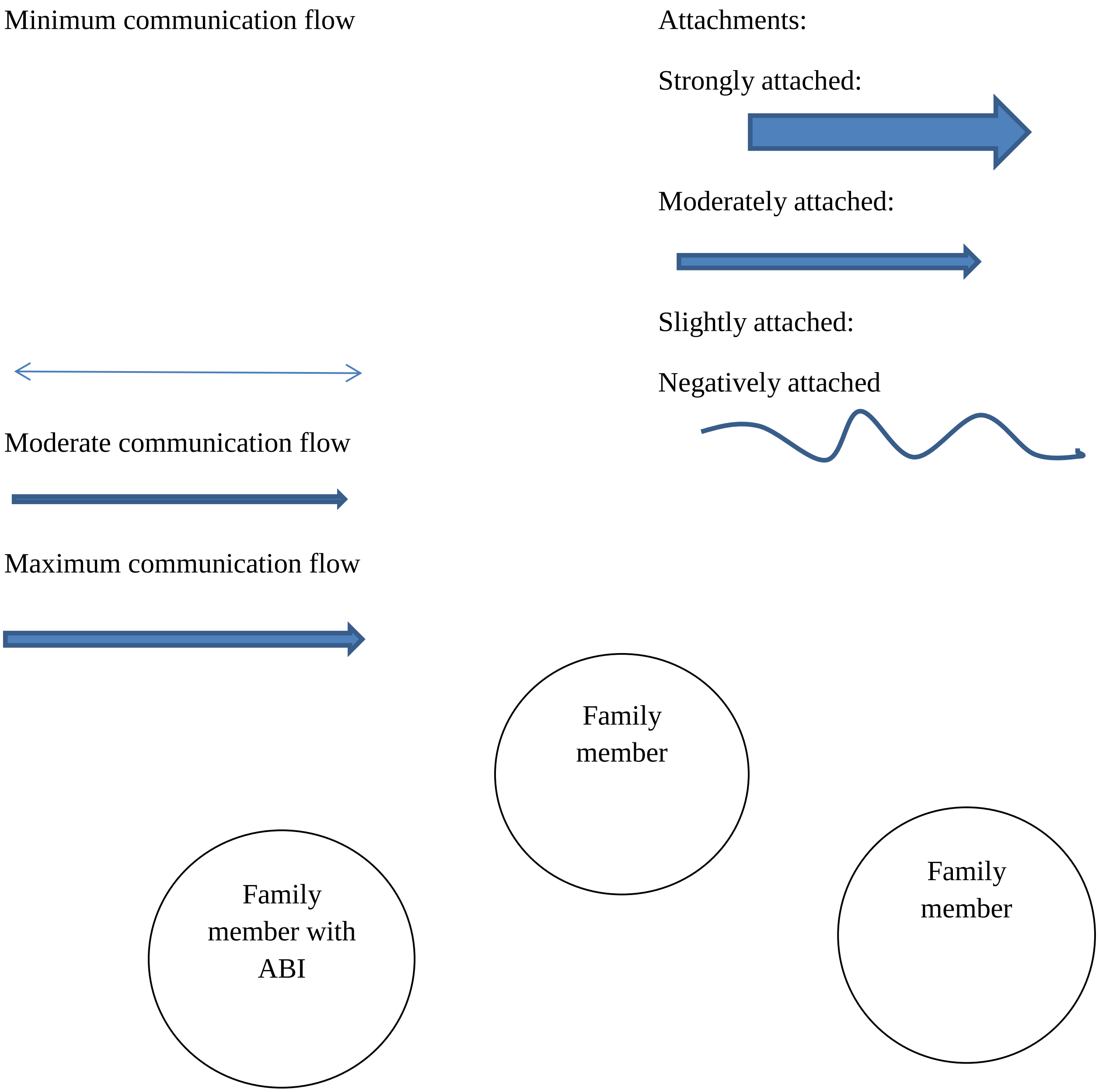
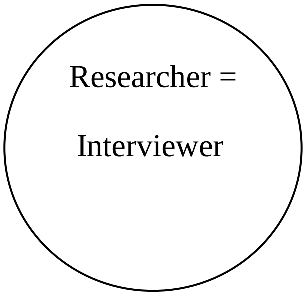
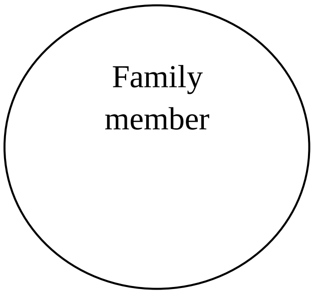
Appendix H

Family Group Observation Sociogram







Individual participants' emotional tone and body language will also be recorded on this form.

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Appendix I

Recruitment Materials (all using above letterhead)

Manitoba Brain Injury Association

Presentation Script

Hello, my name is Jane Karpa. I am a doctoral student at the University of Manitoba and this research is being conducted to complete my thesis. I appreciate you taking the time to come out and listen to me tell you about my research project called: Families' experiences living with ABI. I believe you can appreciate that acquired brain injury can dramatically impact individuals and families. ABI can lead to disruptions in the thinking, feeling and behaving of the loved one with the ABI. These disruptions, often not visible, can directly impact individuals' and families' experiences and lead to an overwhelming sense of loss. My husband suffered an ABI. Although he was visibly the same, I and family members noticed differences, changes in his actions, thinking and feelings. "He was there yet not there" – I and family members become overwhelmed, stressed, depressed, and we faced increasing financial and social burdens. My role shifted from spouse to parent; I experienced lack of social support as friends and some family members dropped away; and I became extremely stressed and burdened. My experiences ended with his death 10 years ago. The impetus for this study has risen from my own experiences as well from the voices of other families affected by ABI.

As a researcher I want to learn from both individuals and family members together as a group about your experiences living with ABI - your perspectives and loss experiences. Having brain injury survivors and family members together for joint interviews will be different than how previous studies have been done – as previous studies have focused on perspectives from the survivors and individual family members - mainly the primary caregivers. I hope that information gained from the stories you choose to tell me will help health care professionals support the entire family system and not just individuals.

I am inviting you to consider taking part in this study.

I would like to recruit five –six families that come from different regions of the province of Manitoba to interview. The definition of family that I am using is: a family is who they believe themselves to be – therefore for this study family will consist of at least the individual member with the ABI and up to a maximum of four other self-defined family members. You will determine which of your family members participate. To help you in your selection process, please think about the following guidelines:

Family participants can include: persons who support, share a history and a future, and are committed and caring towards each other. Neither the individual member with the ABI nor the other family members need to be residing within the same household. Participants can include friends as well as biological and legal family member participants.

Inclusion criteria for the brain injured members are:

- Medical diagnosis of a mild to severe brain injury
- ABI event is NOT a result of or is not associated with a progressive neurological disorder or degenerative brain disease (i.e. Alzheimer’s or other forms of dementia). ABI may include trauma (i.e. motor vehicle accident falls, assault, and sports injury), vascular, one-time toxic events, anoxia, infection and tumor.
- Minimum two years after injury
- Living in the community
- English language communication skills
- Need to be a minimum of 18 years of age at the time the study is conducted
- Need to be able to give informed consent

Inclusion criteria for perceived family members:

- Minimum two years of experiences after the initial brain injury
- Family members do not need to be residing in the same household.

- Family members need to be a minimum of 18 years of age at the time the study is conducted
- English language communication skills

There will be a maximum of two conjoint in-depth face to face interviews. The first interview will be approximately two-three hrs. in length. If you choose to participate in the 2nd interview it will be approximately 1hr. long. You will be offered a choice on the location for the interviews. The interviews will be digitally audio-recorded and transcribed through a designated transcriptionist.

During the beginning of the first interview I will collect demographic information about your family. I will ask questions concerning the age, occupation, education of each family member, as well as ABI diagnosis, post injury time and family constellation information. I will also be collecting information on your families' contact with larger systems and how you communicate with each other. Following the gathering of this information you will then be asked to think about your life experiences with ABI as three life stage chapters in a book about their family. The first chapter is about your family life before the ABI event, the second chapter is now – living with ABI, and chapter three concerns your future family life. I will then be asking you to tell me about different family events or situations that you experienced during each of these chapters.

The second interview will be scheduled to take place two-three weeks following the first interview. The purpose of the less structured second interview is to follow up with your families' reflections from the first interview, clarify uncertainties and any additional perspectives and experiences you wish to relate. To help you to remember what you said in the first interview facilitate I will review the transcript and provide you with points made in their first interview for you to review in advance. The second interview, held in the same location as the first interview, will also be audio recorded and transcribed.

Your participation is a choice, your consent is voluntary and you may choose to withdraw from the study at any time with no repercussions. In recognition for your time and to offset some transportation costs, each family member will be offered $25 for participating. Findings from this thesis research may be published in an academic journal and presentations will be given locally, nationally and internationally. In any publications or presentations about the study findings, I will aim to secure that participant identities remain confidential. Only participant and family pseudonyms will be used. Care will be taken to endeavor that any quotes used from the data to present the study findings contain no identifying information in order to protect families' privacy.

If you are interested in participating in this project, I am handing out a form highlighting information about this thesis research project for you to take home, think about and share with others whom you think may also be interested. This form also has my contact information on it for you to initiate contact.

Questions?

Research Project Description and Researcher Contact Information

Title of research project: Families' experiences living with ABI.

As a researcher I want to learn from both individuals and family members together as a group about your experiences living with ABI - your perspectives and loss experiences. Having brain injury survivors and family members together for joint interviews will be different than how previous studies have been done – as previous studies have focused on perspectives from the survivors and individual family members - mainly the primary caregivers. I hope that information gained from the stories you choose to tell me will help health care professionals support the entire family system and not just individuals.

I am inviting you to consider taking part in this study.

I am would like to recruit five –six families that come from different regions of the province of Manitoba to interview. The definition of family that I am using is: a family is who they believe themselves to be – therefore for this study family will consist of at least the individual member with the ABI and up to a maximum of four other self-defined family members. You will determine which of your family members participate. To help you in your selection process, please think about the following guidelines:

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- ABI event is NOT a result of or is not associated with a progressive neurological disorder or degenerative brain disease (i.e. Alzheimer's or other forms of dementia). ABI may include trauma (i.e. motor vehicle accident falls, assault, and sports injury), vascular, one-time toxic events, anoxia, infection and tumor.
- Minimum two years after injury
- Living in the community
- English language communication skills
- Need to be a minimum of 18 years of age at the time the study is conducted
- Need to be able to give informed consent

Inclusion criteria for perceived family members:

- Minimum two years of experiences after the initial brain injury
- Up to 5 family members
- Family members do not need to be residing in the same household.
- Family members need to be a minimum of 18 years of age at the time the study is conducted
- English language communication skills

There will be a maximum of two conjoint in-depth face to face interviews. The first interview will be approximately two-three hrs. in length. If you choose to participate in the 2nd interview it will be approximately 1hr. long. You will be offered a choice on the location for the interviews. The interviews will be digitally audio-recorded and transcribed through a designated transcriptionist.

During the beginning of the first interview I will collect demographic information about your family. I will ask questions concerning the age, occupation, education of each family member, as well as ABI diagnosis, post injury time and family constellation information. I will also be collecting information on your families' contact with larger systems and how you communicate with each other. Following the gathering of this information you will then be asked to think about your life experiences with ABI as three life stage chapters in a book about their family. The first chapter is about your family life before the ABI event, the second chapter is now – living with ABI, and chapter three concerns your future family life. I will then be asking you to tell me about different family events or situations that you experienced during each of these chapters.

The second interview will be scheduled to take place two-three weeks following the first interview. The purpose of the less structured second interview is to follow up with your families' reflections from the first interview, clarify uncertainties and any additional perspectives and experiences you wish to relate. To help you to remember what you said in the first interview facilitate I will review the transcript and provide you with points made in their first interview for you to review in advance. The second interview, held in the same location as the first interview, will also be audio recorded and transcribed.

Your participation is a choice, your consent is voluntary and you may choose to withdraw from the study at any time with no repercussions. In recognition for your time and to offset some transportation costs, each family member will be offered $25 for participating. Findings from this thesis research may be published in an academic journal and presentations will be given locally, nationally and internationally. In any publications or presentations about the study findings, I will aim to secure that participant identities remain confidential. Only participant and family pseudonyms will be used. Care will be taken to endeavor that any quotes used from the data to present the study findings contain no identifying information in order to protect families' privacy.

If you are interested in participating in the interview component of this doctoral research project please contact Jane Karpa (the principal researcher) at email: umkarpaj@myumanitoba.ca and or phone: [redacted]

December 13, 2016

David Sullivan, MSW

Manitoba Brain Injury Association
Executive Director
204-825 Sherbrook Street
Winnipeg, Manitoba R3A 1M5

Dear Mr. Sullivan:

I am writing to inform you about a study and to request permission to recruit participants through the Manitoba Brain Injury Association. As you are aware, I am interested in examining families' experiences living with ABI. I am a doctoral student with the Applied Health Science program at the University of Manitoba and I have received funding from the Manitoba Centre for Nursing and Health Research grants program to support the study "*Families' Experiences Living with Acquired Brian Injury: A Narrative Inquiry Study.*" The purpose of the study is to examine families' experiences living with ABI; how they experience ABI as an ambiguous loss event, and explore the impact of ABI on families' attitudes, beliefs and identity. I plan to hold two interviews with individual brain injury survivors conjointly with members of their family to talk about family experiences based on stories surrounding events and times before the brain injury, after the brain injury and future expectations.

I would like to meet with you and or others who are in a position to help co-ordinate and distribute invitations to attend public presentations (in Winnipeg, Brandon, and Dauphin) about this research project. The purpose of the meeting would be to describe the study and inclusion criteria and address any questions about the study. I would also like to explore with you the possibility of available space at MBIA sites to conduct my presentations. I will contact you shortly to follow-up on this request.

Thank you for your consideration.

Sincerely,

Jane Karpa, RPN, MMFT, PhD(c)
Applied Health Sciences Program
Faculty of Graduate Studies University of Manitoba
email: umkarpaj@myumanitoba.ca
phone: [redacted]

The Education and Nursing Research Ethics Board has approved this research; and the contact information for the Human Ethics Coordinator (HEC) at the University of Manitoba is (humanethics@umanitoba.ca and 204-474-7122).

Recruitment Materials

Stroke Recovery Association of Manitoba

January 4, 2017

Diane O’Neil
Stroke Association of Manitoba
Executive Director
Unit B-247 Provencher Boulevard
Winnipeg, MB R2H 0G6

Dear Ms. O’Neil:

I am writing to inform you about a study and to request permission to recruit participants through the Stroke Recovery Association of Manitoba. As you are aware, I am interested in examining families’ experiences living with ABI. I am a doctoral student with the Applied Health Science program at the University of Manitoba and I have received funding from the Manitoba Centre for Nursing and Health Research grants program to support the study “*Families’ Experiences Living with Acquired Brian Injury: A Narrative Inquiry Study.”* The purpose of the study is to examine families’ experiences living with ABI; how they experience ABI as an ambiguous loss event, and explore the impact of ABI on families’ attitudes, beliefs and identity. I plan to hold two interviews with individual brain injury survivors conjointly with members of their family to talk about family experiences based on stories surrounding events and times before the brain injury, after the brain injury and future expectations.

I would like to meet with you and or others who are in a position to help co-ordinate and distribute an invitation to attend a public presentation in Winnipeg, about this research project, as well as posting the project description on SRAM’s website and Facebook page and in an email distributed to the SRAM service users. The purpose of the meeting would be to describe the study and inclusion criteria and address any questions about the study. I would also like to explore with you the possibility of available space at SRAM to conduct my presentation. I will contact you shortly to follow-up on this request.

Thank you for your consideration.

Sincerely,

Jane Karpa, RPN, MMFT, PhD(c)

Notice of Invitation to Attend Public Presentation

Are you interested in learning about a research project seeking to explore families' perspectives and loss experiences living with an acquired brain injury?

An invitation is extended to all those experiencing living with an acquired brain injury - survivors, family members, and friends to attend a public presentation given by Ms. Jane Karpa a doctoral student at the University of Manitoba. Ms. Karpa will be letting you know about an upcoming study called: Families' experiences living with ABI. The purpose of the study is to examine families' experiences living with ABI so that health care professionals and agencies can better understand families' perspectives. Understanding of family perspectives can inform family-centered care.

Ms. Karpa has her own experiences of living with ABI, and during her presentation she will briefly share her experiences, qualifications and background. Further information about the study including participation criteria, how data will be collected and participation time commitments will be provided.

1) If you are interested, please consider attending the following presentation.

Winnipeg location –date and time yet to be established

Also, if you know of any other family, not a part of the Stroke Recovery network, please consider passing on this invitation to them.

The Education and Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project you may contact Jane Karpa [redacted]; umkarpaj@myumanitoba.ca), or her research supervisor, Dr. Wanda Chernomas ([redacted] Wanda.Chernomas@umanitoba.ca) and the Human Ethics Coordinator (HEC) at the University of Manitoba [redacted]

Presentation Script

Hello, my name is Jane Karpa. I am a doctoral student at the University of Manitoba and this research is being conducted to complete my thesis. I appreciate you taking the time to come out and listen to me tell you about my research project called: Families' experiences living with ABI. I believe you can appreciate that acquired brain injury can dramatically impact individuals and families. ABI can lead to disruptions in the thinking, feeling and behaving of the loved one with the ABI. These disruptions, often not visible, can directly impact individuals' and families' experiences and lead to an overwhelming sense of loss. My husband suffered an ABI. Although he was visibly the same, I and family members noticed differences, changes in his actions, thinking and feelings. “He was there yet not there” – I and family members became overwhelmed, stressed, depressed, and we faced increasing financial and social burdens. My role shifted from spouse to parent; I experienced lack of social support as friends and some family members dropped away; and I became extremely stressed and burdened. My experiences ended with his death 10 years ago. The impetus for this study has risen from my own experiences as well from the voices of other families affected by ABI.

As a researcher I want to learn from both individuals and family members together as a group about your experiences living with ABI - your perspectives and loss experiences. Having brain injury survivors and family members together for joint interviews will be different than how previous studies have been done – as previous studies have focused on perspectives from the survivors and individual family members - mainly the primary caregivers. I hope that information gained from the stories you choose to tell me will help health care professionals support the entire family system and not just individuals.

I am inviting you to consider taking part in this study.

I would like to recruit five –six families that come from different regions of the province of Manitoba to interview. The definition of family that I am using is: a family is who they believe themselves to be – therefore for this study family will consist of a **maximum** of 5 family participants, per family unit, including the member with the ABI; or-a **minimum** of 3 participants for each family group, including the member with the brain injury. You will determine which of your family members participate. To help you in your selection process, please think about the following guidelines:

Family participants can include: persons who support, share a history and a future, and are committed and caring towards each other. Neither the individual member with the ABI nor the other family members need to be residing within the same household. Participants can include friends as well as biological and legal family member participants.

All participants need to be over the age of 18, able to speak and read English and willing to participate in a family group interview. For the individual with the ABI, the individual needs to be living in the community, a minimum of two years after the initial brain injury event, and medically stable.

There will be a maximum of two face to face interviews with all family participants. The first interview will be approximately two-three hrs. in length. A brief break during this interview can occur if you need one. If you choose to participate in the 2nd interview it will be approximately 1hr. long. You will be offered a choice on the location for the interviews. The interviews will be digitally audio-recorded and transcribed through a designated transcriptionist.

During the beginning of the first interview I will collect demographic information about your family. I will ask questions concerning the age, occupation, education of each family member, as well as ABI diagnosis, post injury time and family constellation information. I will also be collecting information on your families' contact with larger systems and how you communicate with each other. Following the gathering of this information you will then be asked to think about your life experiences with ABI as three life stage chapters in a book about their family. The first chapter is about your family life before the ABI event, the second chapter is now – living with ABI, and chapter three concerns your future family life. I will then be asking you to tell me about different family events or situations that you experienced during each of these chapters.

The second interview will be scheduled to take place three-four weeks following the first interview. The purpose of the less structured second interview is to follow up with your families' reflections from the first interview, clarify uncertainties and any additional perspectives and experiences you wish to relate. To help you to remember what you said in the first interview facilitate I will review the transcript and provide you with points made in their first interview for you to review in advance. The second interview, held in the same location as the first interview, will also be audio recorded and transcribed.

Your participation is a choice, your consent is voluntary and you may choose to withdraw from the study at any time with no repercussions. In recognition for your time and to offset some transportation costs, each family member will be offered $25 in cash for participating. Findings from this thesis research may be published in an academic journal and presentations will be given locally, nationally and internationally. In any publications or presentations about the study findings, I will aim to secure that participant identities remain confidential. Only participant and family pseudonyms will be used. Care will be taken, such that any quotes used from the data to present the study findings contain no identifying information in order to protect families' privacy.

If you are interested in participating in this project, I am handing out a form highlighting information about this thesis research project for you to take home, think about and share with others whom you think may also be interested. This form also has my contact information on it for you to initiate contact.   Questions?

Invitation to Consider Participation in a Research Project: Distributed and Dissemination via Email

By the Stroke Recovery Association of Manitoba

Enclosed is an invitation to participate in a research study being conducted by Jane Karpa, a doctoral student at the University of Manitoba. The title of her Research Project is: Families' Experiences Living with ABI: A Narrative Inquiry Study.

The purpose of the study is to examine families' experiences living with ABI so that health care professionals and agencies can better understand families' perspectives.

Please consider participating in this study.

Video Presentation Script

Hello, my name is Jane Karpa. I am a doctoral student at the University of Manitoba who is conducting a study as part of the thesis requirement of my program. I'm making this video to share information about my study in order to invite families to consider participating. I appreciate you taking the time to watch this video about my research project called: Families' experiences living with Acquired Brain Injury.

Acquired Brain Injury is most frequently defined as damage to the brain which occurs after birth and may be caused by: 1) a traumatic event-a result of a motor vehicle collision, fall, assault or sports injury; or 2) a non-traumatic event such as stroke, aneurysm, infection of the brain, and or a tumour. Acquired brain injury or ABI (for short) is not related to: a genetic disorder; a developmental disability (e.g. Down's syndrome); or a process which progressively damages the brain (e.g. Alzheimer's, multiple sclerosis).

I believe you can appreciate that acquired brain injury resulting from a stroke can dramatically impact individuals and families. ABI can lead to disruptions in the thinking, feeling and behaving of the loved one with the ABI. These disruptions, often not visible, can directly impact individuals' and families' experiences and lead to an overwhelming sense of loss. My husband suffered an ABI as a result from a stroke with multiple bleeds. Although he was visibly the same, I and family members noticed differences, changes in his actions, thinking and feelings. “He was there yet not there” – I and family members became overwhelmed, stressed, depressed, and we faced increasing financial and social burdens. My role shifted from spouse to parent; I experienced lack of social support as friends and some family members dropped away; and I became extremely stressed and burdened. My experiences ended with his death 10 years ago. The impetus for this study has risen from my own experiences as well from the voices of other families affected by ABI.

As a researcher I want to learn from both individuals and family members together as a group about your experiences and perspectives living with ABI. Having brain injury survivors and family members together for joint interviews will be different than how previous studies have been done – as previous studies have focused on perspectives from the survivors and individual family members - mainly the primary caregivers. I hope that information gained from the stories you choose to tell me will contribute to help health care professionals support the entire family system and not just individuals.

I am inviting you to consider taking part in this study. I would like to recruit five –six families that come from different regions of the province of Manitoba to interview. The definition of family that

I am using is: a family is who they believe themselves to be – therefore for this study family will consist of a **maximum** of 5 family members as participants, per family unit, including the member with the ABI; or-a **minimum** of 3 participants for each family group, including the member with the brain injury. You will determine which of your family members participate. To help you in your selection process, please think about the following guidelines:

Family participants can include: persons who support, share a history and a future, and are committed and caring towards each other. Neither the individual member with the ABI nor the other family members need to be residing within the same household. Participants can include friends as well as biological and legal family member participants.

All participants need to be over the age of 18, able to speak and read English and willing to participate in a family group interview. For the individual with the ABI, the individual needs to be living in the community, a minimum of two years after the initial brain injury event, and medically stable.

There will be a maximum of two face to face interviews with all family participants. The first interview will be approximately two-three hrs. in length. A brief break during this interview can occur if you need one. If you choose to participate in the 2nd interview it will be approximately 1hr. long. You will be offered a choice on the location for the interviews. The interviews will be digitally audio-recorded and transcribed through a designated transcriptionist.

During the beginning of the first interview I will collect general information about your family. I will ask questions concerning the age, occupation, education of each family member, as well as ABI diagnosis, post injury time and family membership information. I will also be collecting information on your families' contact/connections with other agencies or organizations, and how you communicate with each other. Following the gathering of this information you will then be asked to think about your life experiences with ABI as three life stage chapters in a book about your family. The first chapter is about your family life before the ABI event, the second chapter is now – living with ABI, and chapter three concerns your future family life. I will then be asking you to tell me about different family events or situations that you experienced during each of these chapters.

The second interview will be scheduled to take place three-four weeks following the first interview. The purpose of the less structured second interview is to follow up with your families' reflections from the first interview, clarify uncertainties and any additional perspectives and experiences you wish to relate. To help you to remember what you said in the first interview I will review the transcript and provide you with points made in their first interview for you to review in advance. The second interview, held in the same location as the first interview, will also be audio recorded and transcribed.

Your participation is a choice, your consent is voluntary and you may choose to withdraw from the study at any time with no repercussions. In recognition for your time and to offset some transportation costs, each family member will be offered $25 in cash for participating. Findings from this thesis research may be published in an academic journal and presentations will be given locally, nationally and internationally. In any publications or presentations about the study findings, I will aim to secure that participant identities remain confidential. Only participant and family fake names will be used. Care will be taken, such that any quotes used from the data to present the study findings contain no identifying information in order to protect families' privacy.

If you are interested in participating in this project or would like further information, please contact me (Jane Karpa) at: email umkarpaj@myumanitoba.ca OR [redacted] (my contact information will also be shown on the video screen). The Education and Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project you may contact myself or Dr. Wanda Chernomas, my thesis advisor ([redacted]); Wanda.Chernomas@umanitoba.ca) or the Human Ethics Coordinator (HEC) at the University of Manitoba (474-7122)

Link to Video:

https://www.youtube.com/watch?v=nXYipEsjLAc

Description of Research Project for Publication in the Stroke Recovery Association of Manitoba Newsletter (Online and Print Versions)

Families' Experiences Living with Acquired Brain Injury

Jane Karpa, a doctoral student at the University of Manitoba, is conducting a study as part of the thesis requirement for her program. The purpose of her study is to examine families' experiences living with Acquired Brain Injury so that health care professionals and agencies can better understand families' perspectives. Understanding of family perspectives can inform family-centered care.

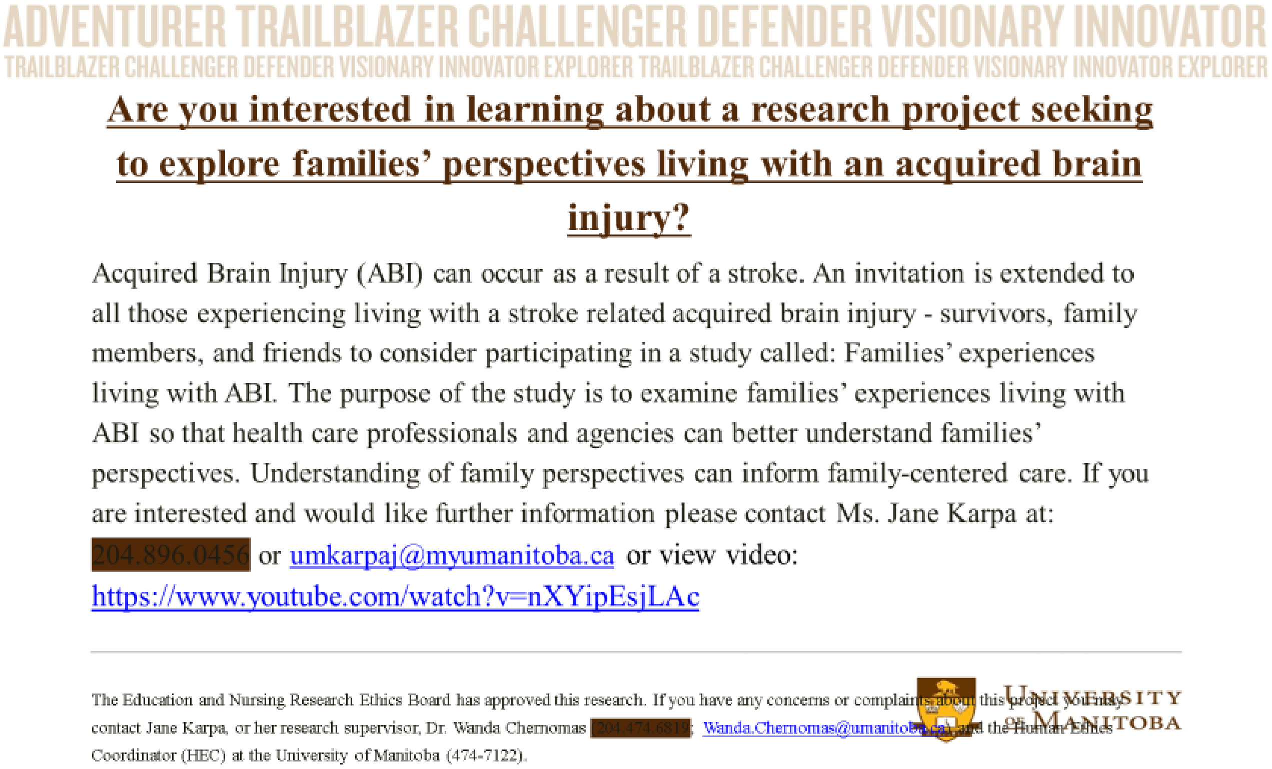
Acquired Brain Injury is most frequently defined as damage to the brain which occurs after birth and may be caused by: 1) a traumatic event-a result of a motor vehicle collision, fall, assault or sports injury; or 2) a non-traumatic event such as stroke, aneurysm, infection of the brain, and or a tumour. Acquired brain injury or ABI (for short) is not related to: a genetic disorder; a developmental disability (e.g. Down's syndrome); or a process which progressively damages the brain (e.g. Alzheimer's, multiple sclerosis).

Ms. Karpa's husband suffered an ABI as a result from a stroke with multiple bleeds. Therefore, she believes that acquired brain injury resulting from a stroke can dramatically impact individuals and families. As a researcher, Ms. Karpa wants to learn from both individuals and family members together as a group about their experiences and perspectives living with ABI.

If you are interested in considering participating in this study and would like further information please contact Ms. Jane Karpa at: [redacted] or umkarpaj@myumanitoba.ca

The Education and Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project you may contact Jane Karpa, or her research supervisor, Dr. Wanda Chernomas ([redacted]; Wanda.Chernomas@umanitoba.ca) and the Human Ethics Coordinator (HEC) at the University of Manitoba ([redacted]

Poster



ADVENTURER TRAILBLAZER CHALLENGER DEFENDER VISIONARY INNOVATOR
TRAILBLAZER CHALLENGER DEFENDER VISIONARY INNOVATOR EXPLORER TRAILBLAZER CHALLENGER DEFENDER VISIONARY INNOVATOR EXPLORER

Are you interested in learning about a research project seeking to explore families' perspectives living with an acquired brain injury?

Acquired Brain Injury (ABI) can occur as a result of a stroke. An invitation is extended to all those experiencing living with a stroke related acquired brain injury - survivors, family members, and friends to consider participating in a study called: Families' experiences living with ABI. The purpose of the study is to examine families' experiences living with ABI so that health care professionals and agencies can better understand families' perspectives. Understanding of family perspectives can inform family-centered care. If you are interested and would like further information please contact Ms. Jane Karpa at: [redacted] or umkarpaj@myumanitoba.ca or view video: https://www.youtube.com/watch?v=nXYipEsjLAc

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The Education and Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project you may contact Jane Karpa, or her research supervisor, Dr. Wanda Chernomas [redacted]; Wanda.Chernomas@umanitoba.ca, and the Human Ethics Coordinator (HEC) at the University of Manitoba (474-7122).

UNIVERSITY OF MANITOBA

September 19, 2017
Diane O'Neil
Stroke Association of Manitoba
Executive Director
Unit B-247 Provencher Boulevard
Winnipeg, MB R2H 0G6

Dear Ms. O'Neil:

The University of Manitoba Education and Nursing Research Ethics Board previously granted us permission to upload my project video to the SRAM website and Facebook page. I have just become aware that the SRAM also has a YouTube channel. With your permission I would like to post my video on this channel. As well, I am also seeking your permission to share the video YouTube link with the Winnipeg and Brandon Chapters of the Manitoba Brain Injury Society and with some in my collegial community network who personally know families living with ABI who are not attached to an organization and maybe interested in learning about my project.

Thank you for your consideration. I look forward to hearing from you.

Sincerely,

Jane Karpa, RPN, MMFT, PhD(c)

Applied Health Sciences Program

Faculty of Graduate Studies University of Manitoba

email: umkarpaj@myumanitoba.ca

phone: [redacted]

The Education and Nursing Research Ethics Board has approved this research; and the contact information for the Human Ethics Coordinator (HEC) at the University of Manitoba is (humanethics@umanitoba.ca and 204-474-7122).

Recruitment Materials: Colleagues

September XX, 2017
Dr. XXXXX
Address

Dear XXX:

In our recent informal conversation about my research project titled: *Families' Experiences Living with Acquire Brain Injury*, you informed me that you personally know of several families living with ABI. I am inviting you to share my project video YouTube link and description with these families.

To support you in your email communication with these families, I have provided a script for you to use (see below). I also request you advise me of the number of families to whom you shared my recruitment materials.

a. *Dear XXX: Recently, I had an informal conversation with a colleague of mine (Jane Karpa) who told me about her research project called "Families' experiences living with acquired brain injury". The purpose of her study is to examine families' experiences living with ABI so that health care professionals and agencies can better understand families' perspectives. This study has received approval from the University of Manitoba Education and Nursing Research Ethics Board. If you are*

> *interested I am sharing the link to her video talking about her project and have also attached a project description. If you would like further information please contact Ms. Jane Karpa a doctoral student at the University of Manitoba at:* [redacted] *or* umkarpaj@myumanitoba.ca *Best wishes, XXX*

Thank you for your encouragement and recruitment assistance.

Sincerely,

Jane Karpa, RPN, MMFT, PhD(c)
Applied Health Sciences Program
Faculty of Graduate Studies University of Manitoba
email: umkarpaj@myumanitoba.ca
phone: [redacted]
The Education and Nursing Research Ethics Board has approved this research; and the contact information for the Human Ethics Coordinator (HEC) at the University of Manitoba is (humanethics@umanitoba.ca and 204-474-7122).

Recruitment Materials
Community Newspapers

Are you interested in learning about a research project seeking to explore families' experiences and perspectives living with an acquired brain injury?

An invitation is extended to all those experiencing living with an acquired brain injury – survivors, family members, and friends to consider participating in a study called: Families' experiences living with ABI.

The purpose of the study is to examine families' experiences living with ABI so that health care professionals and agencies can better understand families' perspectives. Understanding of family perspectives can inform family-centered care.

If you are interested and would like further information please contact:
Ms. Jane Karpa a doctoral student at the University of Manitoba
[redacted] or umkarpaj@myumanitoba.ca The Education and Nursing Research Board has approved this research.

Recruitment Materials
Independent Living Resource Centre

November 7, 2017

John Young
Executive Director
393 Portage Ave #311A

Winnipeg, MB R3B 3H6

Dear Mr. Young:

I am writing to follow up with you from our previous phone conversation. about my study and the request to recruit participants through the Independent Living Resource Centre of Winnipeg. As you are aware, I am interested in examining families' experiences living with ABI. I am a doctoral student with the Applied Health Science program at the University of Manitoba and I have received funding from the Manitoba Centre for Nursing and Health Research grants program to support the study "*Families' Experiences Living with Acquired Brian Injury: A Narrative Inquiry Study.*" The purpose of the study is to examine families' experiences living with ABI; how they experience ABI as an ambiguous loss event, and explore the impact of ABI on families' attitudes, beliefs and identity. I plan to hold one-two interviews with individual brain injury survivors conjointly with members of their family to talk about family experiences based on stories surrounding events and times before the brain injury, after the brain injury and future expectations.

During our previous communication you agreed to share a description of my project with your staff and clients and display a poster about my project on site. I have attached a copy of the project description and poster. I would like the opportunity to meet directly with yourself and staff members, to further explain my project, so that staff will be able to guide potential participants to the project information. I will contact you shortly to follow up with my meeting request. Thank you for your consideration and support.

Sincerely,

Jane Karpa, RPN, MMFT, PhD(c)
Applied Health Sciences Program
Faculty of Graduate Studies University of Manitoba
email: umkarpaj@myumanitoba.ca
phone: [redacted]

The Education and Nursing Research Ethics Board has approved this research; and the contact information for the Human Ethics Coordinator (HEC) at the University of Manitoba is (humanethics@umanitoba.ca and 204-474-7122).

Recruitment Materials
Manitoba League for Persons with Disabilities

November 7, 2017

Ms. Jennifer Sande
Executive Director
909-294 Portage Ave
Winnipeg, MB R3C 0B9

Dear Ms. Sande:

I am writing to follow up with you from our previous phone conversation about my study and the request to recruit participants through the Manitoba League for Persons with Disabilities. As you are aware, I am interested in examining families' experiences living with ABI. I am a doctoral student with the Applied Health Science program at the University of Manitoba and I have received funding from the Manitoba Centre for Nursing and Health Research grants program to support the study "*Families' Experiences Living with Acquired Brian Injury: A Narrative Inquiry Study.*" The purpose of the study is to examine families' experiences living with ABI; how they experience ABI as an ambiguous loss event, and explore the impact of ABI on families' attitudes, beliefs and identity. I plan to hold one-two interviews with individual brain injury survivors conjointly with members of their family to talk about family experiences based on stories surrounding events and times before the brain injury, after the brain injury and future expectations.

During our previous communication you agreed to support project recruitment by sharing a description of my project amongst the staff of the Manitoba League of Person's with Disabilities who maybe interested in participating, and posting a project description and video link on the MLPD member Facebook page. I have attached a copy of the project description for sharing and a shortened version of the project description for posting as well as the video link. Thank you for your consideration and support.

Sincerely,

Jane Karpa, RPN, MMFT, PhD(c)
Applied Health Sciences Program
Faculty of Graduate Studies University of Manitoba
email: umkarpaj@myumanitoba.ca
phone: [redacted]

The Education and Nursing Research Ethics Board has approved this research; and the contact information for the Human Ethics Coordinator (HEC) at the University of Manitoba is (humanethics@umanitoba.ca and 204-474-7122).

Recruitment Materials

Reh-Fit Centre

November 7, 2017

Darlene Lamont
Executive Director
1390 Taylor Ave, Winnipeg, MB R3M 3V8
Dear Ms. Lamont:

I am writing to follow up with you from our previous phone conversation. about my study and the request to recruit participants through the Reh-Fit Centre. As you are aware, I am interested in examining families' experiences living with ABI. I am a doctoral student with the Applied Health Science program at the University of Manitoba and I have received funding from the Manitoba Centre for Nursing and Health Research grants program to support the study "*Families' Experiences Living with Acquired Brian Injury: A Narrative Inquiry Study."* The purpose of the study is to examine families' experiences living with ABI; how they experience ABI as an ambiguous loss event, and explore the impact of ABI on families' attitudes, beliefs and identity. I plan to hold one-two interviews with individual brain injury survivors conjointly with members of their family to talk about family experiences based on stories surrounding events and times before the brain injury, after the brain injury and future expectations.

During our previous communication you agreed to post a description of my project and video link on the Reh-Fit website and in the newsletter. I have attached a copy of the project description and provided you with the video link. If you have any further questions or concerns please contact me. Thank you for your consideration and support.

Sincerely,

Jane Karpa, RPN, MMFT, PhD(c)
Applied Health Sciences Program
Faculty of Graduate Studies University of Manitoba
email: umkarpaj@myumanitoba.ca

phone: [redacted]

The Education and Nursing Research Ethics Board has approved this research; and the contact information for the Human Ethics Coordinator (HEC) at the University of Manitoba is (humanethics@umanitoba.ca and 204-474-7122).

Description of Research Project for Publication by the Reh-Fit Centre; Independent Living Centre; and Manitoba League of Person's with Disabilities

Are you interested in learning about a research project seeking to explore families' perspectives living with an acquired brain injury?

Jane Karpa, a doctoral student at the University of Manitoba, is conducting a study as part of the thesis requirement for her program. The purpose of her study is to examine families' experiences living with Acquired Brain Injury so that health care professionals and agencies can better understand families' perspectives. Understanding of family perspectives can inform family-centered care.

Acquired Brain Injury is most frequently defined as damage to the brain which occurs after birth and may be caused by: 1) a traumatic event-a result of a motor vehicle collision, fall, assault or sports injury; or 2) a non-traumatic event such as stroke, aneurysm, infection of the brain, and or a tumour. Acquired brain injury or ABI (for short) is not related to: a genetic disorder; a developmental disability (e.g. Down's syndrome); or a process which progressively damages the brain (e.g. Alzheimer's, multiple sclerosis).

Ms. Karpa's husband suffered an ABI as a result from a stroke with multiple bleeds. Therefore, she believes that acquired brain injury resulting from a stroke can dramatically impact individuals and families. As a researcher, Ms. Karpa wants to learn from both individuals and family members together as a group about their experiences and perspectives living with ABI.

If you are interested in considering participating in this study and would like further information please contact Ms. Jane Karpa at: [redacted] or umkarpaj@myumanitoba.ca

The Education and Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project you may contact Jane Karpa, or her research supervisor, Dr. Wanda Chernomas (204.474.6819; Wanda.Chernomas@umanitoba.ca) and the Human Ethics Coordinator (HEC) at the University of Manitoba (474-7122).

Appendix J

Permission from John Wiley and Sons

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