UNIVERSITY OF CALGARY

The Experience of Adolescents and Emerging Adults
Living with a Parent with an Acquired Brain Injury

by

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A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF SCIENCE

DIVISION OF APPLIED PSYCHOLOGY
CALGARY, ALBERTA
AUGUST, 2012

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ABSTRACT

Although research studies have investigated the impact of an individual’s acquired brain injury (ABI) on spouses, parents, and siblings, little is known about the experience of adolescent and emerging adult children living with a parent with an ABI. Using heuristic inquiry, this study was undertaken to provide an understanding of what it is like for adolescents and emerging adult children to grow up living with a parent with an ABI. Six sons and daughters, aged 18-32 years, who were adolescents at the time of their parent’s ABI participated in semi-structured interviews. From their narratives, four categories (Impact, Changes in Family System, External Supportive Resources, Coping) were developed to describe the related elements that constitute the experience of living with a parent with an ABI. The findings are discussed in relation to existing literature and new understandings arising from the study. Implications for theory, research, and practice are presented.
ACKNOWLEDGEMENTS

Many individuals and organizations contributed to the creation of this research thesis. I would like to thank my supervisor, Dr. Sharon E. Robertson, for her ability to challenge me and support me on this journey. I would also like to thank the other members of my examination committee, Dr. Jo-Anne Willment and Dr. Theresa Green, for developing challenging and thoughtful questions making my oral examination a pleasant and enriching process. I would like to acknowledge the Social Sciences and Human Research Council (SSHRC) for providing me with the Joseph-Armand Bombardier Canada Graduate Scholarship for Master’s level students. I would like to acknowledge organizations including the Association for the Rehabilitation of the Brain Injured (ARBI), the Southern Alberta Brain Injury Society (SABIS), and the Brain Injury Rehabilitation Centre that provided support and consultation services to this research. I would like to thank my friends and my family for their support and many words of encouragement reminding me of the significance and need for this research. I would also like to thank Jeff Cruz, my life-partner, for his patience, encouragement, support, and understanding that helped maintain my passion for this research.
DEDICATION

I would like to dedicate my thesis to my mom and my siblings who inspired my work, fostered my courage, and enhanced my strength. Without your unconditional support, our stories would be forever hidden, lost, and misunderstood. Your courage and strength inspires and encourages me every day.
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CHAPTER ONE: INTRODUCTION

All of us have had moments in life when we realize our lives have changed forever. It could be high school graduation, getting married, having children, or losing a loved one. We all experience events or non-events in our lives that force us to change, learn, and hopefully grow. These transitions are rarely simple and easy. Human beings like stability and changing can be very difficult for us. However, it is because we change that we always have the opportunity to grow and become better than we were (Goodman, Schlossberg, & Anderson, 2006).

Some transitions carry more importance for some people than for others. I know there have been many important transitions in my life. Graduating from high school was an amazing feat given my situation at the time. Getting into university was even more incredible. Meeting my partner also spurred on other changes in my life. These were all events in my life that I would consider to be important and life-changing. However, none to this day compares to the significance of the changes that occurred because of a single event in my adolescence: my mother’s car accident.

In December 2000, my mother was driving to work after dropping my brother off at the University for his class, when she was T-boned by another car, hitting her on the left side of our car. She broke her left elbow, permanently limiting her movement in that arm. She re-injured her left knee which needed surgery again. My siblings and I were told she had a “mild concussion”, and she was sent home after overnight observation. Over the next few weeks, her communication abilities started to dissolve, her memory got worse, and her emotionality increased. Despite several visits to doctors and specialists, no one could explain her symptoms. Six months later, she was diagnosed with a swelling
of the meninges, resulting in more damage. We were told that she would recover and her abilities would return. When they did not, professionals started to think that they were psychosomatic symptoms. She was not diagnosed with a brain injury until eight years later with the help of my and my sister’s advocacy and the need to investigate her constant migraines. At that point, there was evidence of a past brain injury.

An acquired brain injury (ABI) is defined as the result of an injury to the brain incurred after birth arising from a medical concern (e.g., aneurysm), trauma (e.g., struck by or against objects), illness or infection (e.g., encephalitis), stroke, substance use and abuse, and a lack of oxygen. ABIs are surprisingly common in Alberta. The Alberta Council for Injury Control and Research (ACICR, 2009) calculated that head injuries accounted for an average of 2227 admissions to Alberta hospitals each year between 2006 and 2009. This average only accounted for those individuals who acquired a head injury resulting from trauma, and ignored the ABIs resulting from illness, medical concerns, or substance abuse. Furthermore, this statistic only accounted for those who were admitted to the hospital and ignored those who were not admitted to the hospital, suggesting that this estimate of hospital admission was an under-estimation of the occurrence of ABI in Alberta.

The number of Albertans who suffer from stroke each year has been estimated to be approximately 5500 (Brain Injury Group, 2005). In addition, the number of Albertans estimated to experience a brain injury as a result of other causes, such as illness, infections, tumours, substance use/abuse, a lack of oxygen, and aneurysm, has been reported to be around 3500 each year (Brain Injury Group, 2005). It is clear that ABI is a more severe concern than originally predicted with many people who are not accounted
for by the above estimations. Therefore, the Brain Injury Group (2005) estimated that there are more than 10,000 new cases of ABIs each year. This amounts to 10,000 new people impacted by brain injuries each year with their own individual concerns influencing and being influenced by the multiple systems that surround them. It includes 10,000 families in Alberta that are impacted each year by an individual’s ABI.

The impact of an ABI on the individual, the family, peers, co-workers, and community is profound, especially when one considers that no two people will have the same experience (Langlois, Rutland-Brown, & Wald, 2006). However, some symptoms and common experiences have been documented in the research literature including physical, behavioural, psychological, cognitive, and social symptoms. These symptoms require individuals to adapt, adjust, and cope with the multiple changes occurring in all areas of their lives.

**The Impact of an Acquired Brain Injury**

The symptoms of an ABI vary depending on the severity and location of the injury in the brain. However, it is important to note that how the injury manifests itself is unique to the individual injury. Physical symptoms can include changes in mobility such as a change in gait. As a result, individuals may experience difficulties in coordination in a complex movement such as walking, running, or even balance (Langlois et al., 2006). Furthermore, physical symptoms can also include changes in neurochemistry, resulting in changes in mood and behaviour (Mateer & D’Arcy, 2000). Behavioural symptoms are typically more evident and can include disinhibition, increased aggression, and emotional over- or under-regulation. These symptoms can then lead to other problematic behaviours such as substance use as the individual struggles to cope.
Psychological symptoms resulting from an ABI can include an increased frequency in depressive episodes and anxiety as well as increased feelings of stress (Anson & Ponsford, 2006; Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001). Individuals with ABIs may also experience grief and loss of self as they recognize the changes they have experienced (Orto & Power, 2000; Nochi, 1998). Individuals’ awareness of their ABIs and the changes significantly impacts the extent to which they will experience severe psychological problems (Prigatano, 2005). The more aware individuals are, the more likely they will experience anxiety, depression, and dissatisfaction with their life after their ABIs (Prigatano, 2005).

Cognitive symptoms are also common amongst individuals who have had an ABI, but they are also the most varied symptoms. These symptoms can include changed memory functioning, loss of memory, difficulties in language (i.e., both understanding and communicating using words), difficulties in communication (i.e., understanding and communicating information), and difficulties processing information (Doidge, 2007; Orto & Power, 2000). As a result of many of the cognitive and psychological symptoms, social symptoms also arise such as difficulties in being able to understand social cues (Orto & Power, 2000). Furthermore, the combination of all the symptoms can result in what seems to be a personality change (Yeates, Gracey, McGrath, 2008). The social system becomes strained as friends and family members attempt to support the individual while also adjusting to the person the individual has become (Callaway, Sloan, & Winkler, 2005; Landau & Hissett, 2008; Orto & Power, 2000).
The Impact of an ABI on the Family

When my mother acquired her brain injury, I knew that my family was different, but I did not expect the extent of the changes. My relationships with my family members were different as were the relationships between my family members. Suddenly, my older siblings viewed me as an equal within a year of my mother’s brain injury. My brother and my sister never got along, but then one day after the accident, they simply stopped talking to each other. My brother’s relationship with my mother slowly disintegrated as he struggled to accept the “new mom”. My brother and I became closer despite this rift in the family, yet after a disagreement over a financial issue, he and I became estranged. We had reconnected by the time my mother was officially diagnosed, and we have been rebuilding our relationship ever since. My sister and I continued to become closer as we supported each other through the ordeal.

It seemed as though my family had fallen apart before my eyes and I could not understand why. I spent years wondering how this happened. I searched for information on the impact of parental ABI on the family, and it was disheartening to realize how little research literature was available to explain or better understand the experience. Family systems theory (Lerner & Kreppner, 1989) states that if an individual changes within the family, then the family needs to adjust to compensate for the changes within the individual. As such, families should also be able to adapt to changes resulting from an ABI as it could be argued that families are used to adapting to normal developmental changes. However, this does not seem to be the case because the research literature provides evidence to the contrary.
The research literature is filled with evidence supporting the struggles family members experience while supporting individuals with ABIs (Carnes & Quinn, 2005; Charles, Butera-Prinzi, & Perlesz, 2007; Dausch & Saliman, 2009; Elbaum, 2007a; Florian & Katz, 1991; Kreutzer et al., 2009; Kieffer-Kristensen, Teasdale, & Bilenberg, 2011; Orto & Power, 2000; Webster, Daisley, & King, 1999). These studies indicate an increased risk for family relationship disintegration (Webster et al., 1999), an increased risk for mental health concerns (Carnes & Quinn, 2005), and a potential for exhibiting post-traumatic symptoms (Kelly & Ward, 2011; Kieffer-Kristensen et al., 2011). It is clear that family members impacted by an ABI experience increased levels of stress as they adjust to the changes in the individual with the ABI, the family relationships, and the family roles (Orto & Power, 2000). However, it is important to note that the persons with ABIs being supported in the families in these cited studies were siblings, spouses, or children, not parents. What happens in families in which a parent incurs an ABI? How do the children in such families fare?

Everything my family and I had been through was on par with the literature and yet there was little research regarding the unique circumstances of children having a parent, or a head-of-household figure, with an ABI. Given the impact on family members of a sibling, spouse, or child acquiring a brain injury, it follows that there may be some similarities if a parent acquires a brain injury. However, there were many elements unique to my experience as an adolescent of a parent with an ABI that were missing in the literature. For example, the literature emphasized the negative impacts resulting from caregiving and supporting a family member with an ABI, which leads readers to believe that there is very little good that could come from such a challenging
experience. Being the optimist that I am, I refused to believe that a challenging experience could only yield negative results. However, as I reflected on the challenges of having a parent with an ABI and became more aware of the volatility of adolescence and emerging adulthood, I began to develop an appreciation of the risks associated with youth having lived with a parent with an ABI during this stage of life.

**Adolescence and Emerging Adulthood**

Adolescence is considered a transitional and developmental time period where individuals experience physical, cognitive, psychological, emotional, and social changes (Steinberg, 2005). The combination of these changes has led researchers to believe that this is a time period of storm and stress when adolescents are considered to be immensely vulnerable (Arnett, 1999; Carr, 1999; Steinberg & Morris, 2001). In turn, this has also led to research investigating adolescent resilience (Rutter, 1990), coping styles (Compas, 2004), and the extent of parental influences (Beyers & Goossens, 2008; Cumsille, Darling, Flaherty, & Martinez, 2009; Smits et al., 2008). In recent years, a new developmental phase called emerging adulthood (Arnett, 2006) has been recognized as a second transitional phase during which adolescents learn to become adults, yet are not completely self-reliant as per North American values. Because emerging adulthood could be described as an extension of adolescence yet with more adult-like responsibilities, many of the same qualities of resilience, coping, and parental influences also apply to emerging adults (Masten, Obradovic, & Burt, 2006).

Given variability in adolescent and emerging adult risk and protective factors, some adolescents and emerging adults may be at greater risk of maladaptive and negative results following a parental ABI than those who have many protective factors.
contributing to their resilience. Furthermore, adolescents who are already experiencing a normal developmental transition (Steinberg & Morris, 2001) may also struggle as they adjust to family role changes, family relationship changes, and parental changes resulting from an ABI. Thus, adolescents may experience more stress in comparison to their same aged-peers who are not living with a parent with an ABI. Increased stress has been found to add to adolescent risk factors depending on how adolescents cope with their feelings of stress as well as the stressors (Compas, 2004).

Adolescents continue to be guided by their parents throughout their transition to adulthood (Beyers & Goosens, 2008; Cumsille et al., 2009; Faber, Edwards, Bauer, & Wetchler, 2003; Levitt, Silver, & Santos, 2007; Smits et al., 2008). This is particularly important for areas such as identity development (Beyers & Goosens, 2008) and coping strategies (Carr, 1999). If parents are no longer able to provide this guidance either through direct (i.e., providing advice) or indirect (i.e., modelling) means, then adolescents will turn to other sources for guidance such as their peers, their siblings, the media, or other adult role models (Turner, 2005). If these other influences are not necessarily positive (e.g., deviant peer group), then adolescents are more likely to engage in problematic behaviours such as substance abuse or violence (Levitt et al., 2007). As such, when parents are no longer able to engage in their role as a parent because of the challenges associated with an ABI, the children are more likely to be at increased risk of poor adjustment in adulthood.

A Significant Topic

On the basis of existing literature, it is clear that family members living with an individual with an ABI require additional support as they navigate this experience filled
with multiple changes. Furthermore, children of parents who have acquired a brain injury seem to be at an increased risk of maladaptive development. Yet, as I reflected on my personal experience, I recognized that I managed to successfully overcome this risk to grow into adulthood, and I wanted to know more about how others were able to do the same. I knew that I could not be alone. I also knew that I had had multiple protective factors contributing to my overall resilience. At the same time, I wanted to learn about the challenges faced by others living with a parent with an ABI, what helped them overcome the challenges, and what made it more or less difficult. As a result, I began to explore the topic of being an adolescent or emerging adult living with a parent who has incurred an ABI.

I could find little research to inform the experience of adolescents and emerging adult living with a parent with an ABI. This is problematic because a lack of research leaves professionals with little or no information to guide their practice with adolescents and emerging adults impacted by a parental ABI. I chose this topic not only to share my experience and inform future research and practice, but also to give others the same opportunity to share their story for the same purposes. In order to engage in competent and ethical practice, it is necessary for counselling psychologists and other allied professionals to be aware of the experience of living with a parent with an ABI, and the potential developmental consequences of this phenomenon.

**Research Question and Aims**

I approached my research asking the question: What is it like for adolescents and emergent adult children to grow up living with a parent with an acquired brain injury? My goals for this research were (a) to raise awareness of the adolescent experience of
growing up living with a parent with an ABI in order to improve rehabilitation and
counselling practice directed towards families, (b) to provide the opportunity for
adolescent and emerging adult children to share their stories and experiences with the
professional and academic world, and (c) to improve individuals’ personal awareness and
understanding of their unique experience of living with a parent with an ABI. I hoped
that all three goals would be met while also contributing to the research literature via an
exploratory study and providing a starting point for future research to be conducted.

Because of my personal experience, I chose a qualitative approach called heuristic
inquiry. This research approach requires researchers to use their own experiences with
the phenomenon to both guide and conduct the research. In using this approach, I
expected that I would be able not only to gain more insight into the phenomenon
experienced, but also to gather more information than others might because participants
are more likely to confide in someone who has also experienced the phenomenon.

In the following chapters, I invite you to take part in this journey with me. I
present the relevant scholarly and research literature in Chapter Two. I then discuss
heuristic inquiry as my methodology of choice for the current research in Chapter Three.
I discuss the results of the inquiry in Chapter Four where you will learn more about the
common themes of the experience. Finally, in Chapter Five, I discuss the results in light
of the existing literature and consider implications for theory, research, and practice.
Although this journey was certainly a roller-coaster for me, my only hope is that I may
convey the depth and richness of the stories shared to ensure that you, the reader, will
better understand the trials, tribulations, and victories of adolescents who have lived with
a parent with an ABI.
CHAPTER TWO: LITERATURE REVIEW

After a thorough search of the literature, it was clear that there was little information about the experience of adolescent children who have lived with a parent with a brain injury. The literature has investigated the impact of an individual with an ABI on a parent, the sibling, a caregiver, and a spouse, yet it seems to have ignored the impact on the children. To clarify this gap in our understanding, I will discuss the research literature that is relevant to inform you, the reader, of the complexity of this phenomenon. First, I will discuss the literature to explain the physical, behavioural, cognitive, psychological, and social impact of an ABI on the individual to give you a better understanding of the challenges associated with this kind of injury. Second, I will discuss the theory and literature explaining the concerns that face family members of individuals with ABIs to inform the experience of children living with a parent with an ABI. Thirdly, I will discuss the literature pertaining to adolescence and emerging adulthood as a normal and abnormal transitional time period in human development including the significance of the parent-child relationship, resilience and coping, and the impact of trauma and family crises. Through this process, I will demonstrate the significance, necessity, and importance of the research undertaken here.

The Impact of an Acquired Brain Injury on the Individual

It is important to note the variability in the changes associated with an ABI dependent upon the location of the injury in the brain as well as the severity of the injury (Mateer & D’Arcy, 2000). Location of the injury in the brain will alter the type of symptoms a person may experience. Also, within the same location, ABIs can appear very differently. Severity of an ABI is used diagnostically to indicate the level of
impairment resulting from the injury. This ranges from mild to severe. The severity of the injury is determined by a variety of neuropsychological tests that consider the duration of the post-injury coma and post-injury amnesia while measuring the extent of disability in physical, behavioural, cognitive, psychological, and social functioning (Mateer & D’Arcy, 2000). This, in turn, also determines the person’s level of independence in everyday life tasks and activities. Mild ABI tends to refer to individuals who are able to complete most tasks independently, with a few mild difficulties and some support from aids (Landau & Hissett, 2008). Severe ABI tends to refer to individuals who may have a severe physical and cognitive disability in addition to requiring assistance completing most everyday tasks (Elbaum, 2007a). These labels are used to inform practitioners of the diagnosis of an ABI, as well as the severity of the injury itself.

Despite the diagnostic labelling, each person will experience an ABI in different ways depending on the location and severity of the injury as well as the changes he or she will experience as a result of the injury. The changes that result from the injury can include physical, behavioural, cognitive, psychological, and social changes. Each of these areas will be briefly described in the subsequent sections. It is important to note that the following discussion is only a brief overview of some of the symptoms that impact persons with ABIs in order to help you understand the challenges that the individuals and family members encounter.

**Physical Changes**

An ABI can result in physical complications, depending on the severity and location of the injury. Mobility can occasionally be negatively impacted by an ABI (Langlois et al., 2006). This means that some individuals experience difficulties moving
different parts of their body. Furthermore, some individuals may be able to move their individual body parts, but be unable to combine multiple movements to accomplish a task. For example, walking combines the movement and coordination of the legs, feet, and core, making it a complicated movement to relearn.

In addition, one must also consider the complexity of the physical changes in the brain (Doidge, 2007). After birth, the brain continues to develop and change using a process called neuroplasticity, where the activity and experiences a person has over his or her lifetime change how the brain functions (Doidge, 2007). As a result, an ABI becomes a physical experience that shapes the brain differently and forces the brain to compensate for lost or damaged areas. As such, the individual will experience deficits in neurotransmitter activity affecting mood and energy level (Langlois et al., 2006).

**Behavioural Changes**

Behaviour is often the most noticeable category of changes resulting from an ABI because it is the most obvious and apparent change. The extent and magnitude of the behavioural changes resulting from an ABI varies in that they can be subtle or apparent. The literature often refers to uninhibited behaviour (Anson & Ponsford, 2006; Arango-Lasprilla et al., 2008; Callaway, Sloan, & Winkler, 2005; Langlois et al., 2006), resulting in the individual behaving inappropriately. For example, individuals with ABIs may inappropriately share their feelings of frustration or anger to a complete stranger.

It is also well-documented that many individuals with ABIs also experience increased aggression (Elbaum, 2007a) due to their higher levels of frustration and anger and have few helpful ways to express it given their disinhibition. Individuals with ABIs often struggle to cope with the myriad of changes in their abilities and overall functioning.
(Elbaum, 2007a; Onsworth, et al., 2007). This is because individuals often compare their pre-injury self to their post-injury self, which can result in feelings of sadness, frustration, and anger (Onsworth, et al., 2007). Similarly, researchers have also indicated that individuals with ABIs may also experience difficulties in over- or under-regulating their emotional expression (Elbaum, 2007a; Langlois et al., 2006). Under-regulating emotional experiences can result in increased behavioural expressions of the emotion such as yelling or violence when individuals feel angry, or frequent uncontrollable crying when individuals feel sad. Conversely, it can also result in very little expression of emotional experiences. This lack of expression can result in internalizing or externalizing behaviours such as depression, anxiety, substance use/abuse, and suicidality (Elbaum, 2007a; Simpson & Tate, 2002).

**Cognitive Changes**

There is immense variety in the types of cognitive changes that result from an ABI. One of the most commonly discussed types is change to the individual’s memory (Orto & Power, 2000). Memory loss can be the most disturbing symptom for some individuals because of the meaning they have placed on memory (Howes, Benton, & Edwards, 2005). Memory loss is often associated with losing their pre-injury life and their pre-injury identity (Gracey et al., 2008; Howes et al., 2005; Nochi, 1998) because they can no longer remember parts of their pre-injury life. Furthermore, memory can be further complicated by limited short-term and long-term memory (Orto & Power, 2000). Some individuals experience anterograde amnesia, meaning that they have difficulties making new long-term memories based on their short-term memory of events (Doidge, 2007; Orto & Power, 2000).
In addition, some individuals experience difficulties processing new information, reacting to information, communicating their needs and wants, and understanding language and communication (Doidge, 2007). However, it is important to note that not only is there great variability in the kind of symptoms individuals with ABIs will experience, but the severity of the symptoms can vary from day to day (Doidge, 2007) usually due to fatigue.

**Psychological and Emotional Well-being**

The psychological changes resulting from an ABI are complex as well as immensely variable. Individuals with ABIs frequently experience difficulties with depression, anxiety, substance use, stress, and identity development (Anson & Ponsford, 2006; Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001; Nochi, 1998; Orto & Power, 2000). Depression, anxiety, and substance use are typically related to the individual’s ability to cope with and accept that they have acquired a brain injury (Anson & Ponsford, 2006). This can be similar to a grieving process where individuals with ABIs mourn the life they had, while trying to accept their post-injury life. This process is critical to reconstructing identity after an ABI (Gracey et al., 2008).

Identity is an important component to the recovery process of an adult with an ABI (Cloute et al., 2008; Gracey et al., 2008). Identity typically needs to be deconstructed after the injury because some individuals recognize the changes themselves, meaning they need to reframe their sense of self and identity to accommodate these changes (Cloute et al., 2008; Gracey et al., 2008; Howes et al., 2005; Nochi, 1998; Prati & Pietrantoni, 2009). Practitioners have been encouraged to help the individual mourn his or her pre-injury identity and incorporate the pre-injury identity into the post-
injury identity (Cloute et al., 2008; Elbaum, 2007a; Gracey et al., 2008; Nochi, 1998; Yeates et al., 2008). However, like so many other elements and symptoms of ABI, there is variability depending on the individual, his or her resilience, the changes, his or her self-awareness, and the context.

Social Impact

Unfortunately, as a result of the combination of changes in multiple areas, many people report that a personality change also results from an ABI (Yeates et al., 2008). As such, friends, family, peers, and colleagues often struggle to adjust to an individual who has acquired a brain injury. As a result, many individuals with ABIs lose friends, romantic partners, family relationships (Callaway, Sloan, & Winkler, 2005; Landau & Hissett, 2008; Orto & Power, 2000), coworkers, and peers (Orto & Power, 2000). This is particularly concerning because individuals with ABIs need emotional and social support while experiencing this intensely stressful event in their lives (Webster et al., 1999).

However, because the surrounding social system, including family and friends, does not always receive support when adjusting to the changes in the individual as he or she recovers, it can become too much stress for the system to sustain. Relationships may start to disintegrate and new relationships become more challenging because of the learned feedback that the individual with the ABI is “too much” for any person to manage (Callaway et al., 2005). It is for this reason that research has suggested that ongoing therapeutic intervention would be useful to ease the strain on the individual as well as the social system (Elbaum, 2007b; Judd & Wilson, 1999; Tasker, 2003).

As the primary source of support for individuals with ABI, family members attempt to ensure that the family system continues to function normally to better support
the individual (Carnes & Quinn, 2005; Orto & Power, 2000). However, family members supporting individuals with ABIs also experience considerable strain as they adjust to the changes (Elbaum, 2007b). The physical, behavioural, cognitive, psychological, and social changes combine to result in a different personality (Yeates et al., 2008), sense of self (Nochi, 1998), and personal sense of meaning in life (Elbaum, 2007a). As individuals with ABIs struggle to get to know themselves, their constantly changing limitations, and their strengths, they must also navigate their own sense of self as part of the family. It is because of these challenges that families experience considerable strain when supporting the individual who is attempting to adapt and manage the myriad of changes in abilities, functioning, sense of self, personality, and identity within the family system. If the family is not resilient enough to continue to support the individual with the ABI, the individual may experience problems that could impact his or her overall recovery (Kreutzer et al., 2009; Orto & Power, 2000).

**Impact of An ABI on the Family**

Family members have been described as the primary source of support by numerous authors studying the recovery and rehabilitation process of individuals with ABI (Carnes & Quinn, 2005; Charles, Butera-Prinzi, & Perlesz, 2007; Dausch & Saliman, 2009; Elbaum, 2007b; Kreutzer et al., 2009; Orto & Power, 2000; Webster et al., 1999). Although the literature over the last 20 years indicates that family members are an important element to include in successful rehabilitation efforts (Charles et al., 2007; Florian & Katz, 1991; Landau & Hissett, 2008; Webster et al., 1999), it seems to be a rare practice to include family members (Orto & Power, 2000). This can be due to several reasons such as (a) service providers’ lack of access to relevant and recent
research recommending familial support (Orto & Power, 2000), (b) service providers’ lack of necessary funds to provide familial support (Orto & Power, 2000), or (c) service providers’ lack of awareness of the need to support family members because of a focus on the individual in service provision (Rolland, 1999).

Family members experience considerable stress in response to an individual acquiring a brain injury within the family (Carnes & Quinn, 2005; Charles et al., 2007; Elbaum, 2007b; Landau & Hissett, 2008; Orto & Power, 2000). Under this stress, family members are expected to meet the demands of the individual without difficulties, yet many experience caregiver burnout and intense emotional experiences (Kreutzer et al., 2009; Orto & Power, 2000). To add to the complexity, it seems that family members are not aware of the services available to them (Junqué, Bruna, & Mataro, 1997). Junqué et al. (1997) recognized that families frequently did not receive appropriate information about their family member who had acquired a brain injury in addition to the supports available to them. Therefore, families were left with many questions and uncertainties about their family member with an ABI, the resources they could access for support, and how the individual with an ABI might impact them in the future.

In the following sections, I will discuss theory and research suggesting that family members are seriously impacted by a family member who acquired a brain injury. More specifically, I will discuss family systems theory to shed light on how an individual with an ABI can impact the family system. I will then discuss the research literature that describes the changes in the roles and responsibilities within the family as well as familial relationships. The combination of theory and research literature will be used to inform
the development of an understanding of the experience of adolescent and emerging adult children living with a parent with an ABI.

**The Family Systems-Illness Model**

As a result of the myriad of changes that occur in the individual, family members need to adjust to the changes that subsequently occur within the family system. Kreppner and Lerner (1989) described family system functioning across the lifespan and accounted for natural changes that occur within the family as a result of individual development. Rather than a family role being stable, Kreppner and Lerner described the family roles as fluid and dynamic. For example, a child will gain more responsibilities as they age to prepare them for adulthood and become a greater contributor to the family system. This is considered a normal and gradual role shift (Kreppner & Lerner, 1989). Therefore, this theory suggests that family members should have little difficulty making changes in familial roles because the family members are accustomed to adjusting their roles naturally within the family as the family continues to develop. However, in their theory, Kreppner and Lerner did not account for the sudden and abnormal shift in familial roles resulting from injury, illness, disability, or loss.

Rolland (1994) based the family systems-illness model on the developmental family system model in that family members’ individual development impacts the overall family functioning. However, Rolland accounted for the onset of illness or disability that forces the family to function differently. Rolland described this as a necessary family role shift to accommodate for the family members who can no longer perform their roles to the same extent as they used to. Rolland (1994) explained that not all families will behave the same when challenged with an illness or disability as it will depend on (a) the
type of disability, illness, or loss encountered; (b) the illness, family, and individual life
cycles; and (c) the belief systems of the family, culture, and society.

**Type of disability, illness, or loss.** Rolland (1994) outlined different factors that
would determine the type of disability, illness, or loss as well as the familial reaction.
These factors include onset of the condition (i.e., acute onset or gradual onset) and the
course of the condition (i.e., progressive, constant, and relapsing). An acute onset means
that the condition was sudden, like a stroke, and this kind of onset may require family
members to be flexible to accommodate the injured or ill family member. A gradual
onset means that the condition may gradually worsen, and family members may have the
time to make plans to accommodate for the family member’s changes and gradual
disability. An ABI could have an acute or gradual onset, depending on the cause of the
injury. For example, an ABI caused by trauma or stroke would be considered to have an
acute onset while an ABI caused by illness such as brain cancer or substance abuse may
have a gradual onset.

The course of the illness indicates the progression of the condition. Rolland
(1994) named three categories to explain the course of an illness or disability. The first
category is called a progressive illness in which the individual may gradually worsen
over time as the illness or disability persists, such as dementia or cerebral palsy. The
second category is called a constant illness in which the individual’s condition remains
mostly stable such as a developmental disability or an acquired disability. The third and
final category is called a relapsing illness, where the individual’s condition is
unpredictable with repeating patterns of recovery and relapses, such as bipolar disorder.
In the case of an ABI, this condition begins as a relapsing condition because it results in
considerable instability of symptomology for the first two years (Rolland, 1999). However, it becomes a constant condition as the individual’s condition stabilizes and he or she begins to recover.

**The illness, family, and individual life cycles.** Rolland (1994) explained that illness and disability have various life cycle phases that alter the familial reaction as the illness or disability progresses. The first phase begins upon initial diagnosis when the family may experience an initial crisis. In this case, the family must quickly adapt and adjust family roles to continue meeting familial demands. Families rely heavily on professionals’ competence to help them determine next steps and how to approach the situation. The second phase, called the chronic phase, begins when the illness starts to stabilize, and there is a sense of constancy with some progression and occasional episodic changes resulting from the illness (Rolland, 1994). The final phase, the terminal phase, is only appropriate for those with terminal illnesses. This phase begins when the ill family member begins to deteriorate and the idea of death becomes more of a reality for the individual as well as the family. It is characterized by families making plans to permanently account for the family member’s loss. Families begin the process of saying good bye and letting go.

This illness life cycle outlined by Rolland (1994) is combined with the normal development of the family members (Rolland, 1994). The influence of the development of the family members as well as the family is called the individual and family life cycle. This cycle considers normal human development as a key contributor to family change and adaptation, as is the case in Kreppner and Lerner’s (1989) theory. As family members develop, the family system must adapt to accommodate individual changes.
(Kreppner & Lerner, 1989). The family and individual life cycle impacts how the family will accommodate the individual with the injury or illness.

Rolland (1999) explained that if a parent acquires a disability or an illness during childrearing years, the family is more severely strained than at other times. Rolland (1999) further stated that if the children are older, they are better able to relieve the strain on the parents than add to the stress as they are more independent. However, because incursion of a parental ABI would be considered the beginning of multiple transitions, adolescents would be considered more vulnerable because simultaneous transitions are viewed to be more challenging (Rolland, 1999). Furthermore, adolescents would also experience the loss of a critical source of guidance in their transition as the adult adjusts to an ABI, adding strain to the family, thus encouraging the adolescents to turn to their peer group for assistance and support (Beyers & Goossens, 2008; Smits et al., 2008).

The belief systems of the family, culture, and society. The familial, cultural, and societal beliefs heavily impact the overall distribution of family roles and family adjustment when faced with illness or disability within the family (Rolland, 1994). Beliefs often guide and justify human behaviour, and as such, beliefs can also impact how the family decides to accommodate for the individual with the illness or disability. In traditional gender-role families, for example, the eldest daughter may be expected to take the role of her ill mother if this was believed to be the appropriate thing for her to do. Rolland (1999) explains that this could create considerable resentment as the one child is forced to become an adult suddenly and with little support from other family members. Beliefs about disability, family, and other areas inevitably impact how the family is able
to cope with the multiple issues surrounding illness, disability, and loss. As such, these same beliefs can also impact family resilience (Walsh, 2003).

**The Family Resilience Framework**

Family resilience also contributes to the family’s ability to adapt to disability within the family. Family resilience is similar to individual resilience in that families have risk and protective factors that impact overall family functioning as well as the coping strategies of individual family members (Flach, 1988; Walsh, 2003). Family resilience also contributes to the family’s ability to adapt to disability within the family (Walsh, 2003). Families all experience stressful events resulting in family crises and stress. When under this level of stress, families can strengthen the relationships or the relationships can disintegrate as a result of the degree of resilience the family has.

Walsh (2003) developed a family resilience framework in which she identified nine key processes associated with family resilience. These are divided into three categories: (a) family belief systems, (b) family organizational patterns, and (c) communication and problem-solving processes. The first category, called family belief systems, is similar to the belief systems of the culture, family, and society proposed by Rolland (1994). This category includes making meaning of adversity, a positive outlook, and spirituality or transcendence. The second category, called family organizational patterns, includes the structure and patterns of functioning within the family that can strengthen or weaken the family functioning. This category includes flexibility of the family structure (e.g., open to change, cooperative parenting, etc.), connectedness between family members, and social or economic resources of the family (e.g., balance between work and family life). The third category, called communication and problem
solving processes, concerns the way family members communicate with each other and work together to resolve problems within the family. This category includes clarity of communication and information, open emotional expression between family members, and collaborative problem-solving. All three categories can contribute to or hinder the overall family resilience.

Walsh’s (2003) family resilience framework combined with Rolland’s (1994) family systems-illness model explains the necessity of the changes that occur within the family as well as the unique reactions of each family impacted by an ABI. Family resilience has been found to be a major contributor to strengthening families experiencing high levels of stress (Walsh, 2003) as it helps the family face the problem as a family rather than as an individual. Family resilience is also believed to serve as a protective factor for individual family members experiencing family or non-family related stress (Flach, 1988). Both Walsh’s framework and Rolland’s model allow practitioners to understand how to strengthen the family while providing a framework to better conceptualize the family’s difficulties.

Family Role Changes

As per Rolland’s (1994) family system-illness model, families must change their normal functioning habits and dynamics in response to a family member acquiring a brain injury. This involves changes in roles and responsibilities such as caregiving, financial contributions, and house maintenance. However, a change in these areas, as alluded to by Rolland (1994; 1999) may not always be the most effective or functional way to adjust to an ABI (Elbaum, 2007b). For example, a spouse may suddenly become the caregiver of his or her spouse, taking on a parental role rather than a partner role.
(Elbaum, 2007b). Because this role is considerably different from the pre-injury role, Elbaum (2007b) suggests that spouses frequently have more difficulty adjusting to their loved-ones’ injuries. Therefore, it seems that the pre-injury role is important in understanding the difficulties a family member may experience as his or her role and relationship to the injured family member changes. Furthermore, the new role may become overwhelming for the individual if the individual does not have support from other family members (Rolland, 1999). It is more effective for families to distribute the injured family member’s role evenly across all family members rather than simply relying on one individual to take on the full role (Rolland, 1994).

Several authors have suggested that if a parent acquires a brain injury, the younger children may demand more attention from the caregiving parent (Douglas & Spellacy, 1996; Elbaum, 2007b; Florian & Katz, 1991). However, it is unclear how older children may react to their parent’s injury as few studies have been conducted examining the experience of older children. Some authors suggest that older children may be able to take on more responsibilities and act as a respite caregiver for the primary caregiver (Aldridge, 2008; Florian & Katz, 1991; Kreutzer, et al., 2009). Furthermore, other older children may become the primary caregiver themselves if no other family member will take this role (Elbaum, 2007b; Florian & Katz, 1991). This results in a reversal of roles, where the parent becomes the child, and the child becomes the parent. These children have been referred to in the research literature as “young carers”, whose caring responsibilities exceed what would normally be expected of them (Aldridge, 2008).

With the necessary shift in roles, especially for children, several new relationship and family dynamics may develop. If the child becomes a part-time or full-time
caregiver to his or her parent with an ABI, the parent with an ABI may feel threatened by the child as the child continues to fulfil the parent’s role (Douglas & Spellacy, 1996; Elbaum, 2007b; Florian & Katz, 1991; Orto & Power, 2000). The parent may also feel resentful and guilty for the child’s role shift despite the additional aid and support that he or she is receiving (Aldridge, 2008; Douglas & Spellacy, 1996; Florian & Katz, 1991; Orto & Power, 2000). Therefore, parents with ABIs may react negatively to their children’s aid and new role by potentially rejecting it, thus putting more pressure on themselves as parents to regain their pre-injury roles (Aldridge, 2008). Rolland (1999) suggested that if parents with ABIs are encouraged to maintain a piece of their “parenting” duties, such as offering guidance to their children, this may offset the parents’ feelings of guilt and resentment while helping the parents with ABIs to feel like parents.

As you can imagine, caregiving at a young age may result in multiple negative outcomes as a result of the increased stress levels. Some of these include externalizing problems, such as addiction or drug abuse, physical illness, and violent behaviours, and internalizing problems such as depression and anxiety (Barkmann, Romer, Watson, & Schulte-Markwort, 2007; Kieffer-Kristensen et al., 2011). Fortunately, children of parents with cognitive disabilities or illness also experience positive outcomes as indicated by Aldridge (2008). In some instances, children may take great pride in their ability to help their parent (Aldridge, 2008). However, this is not commonly described in the research literature as most of the literature focuses on the negative impact and the injustice towards these children (Aldridge, 2008). If the literature would also focus on the positive outcome, this might help to better identify how to improve the resilience of
children and youth who may experience more difficulties at home when coping with a parent who has acquired a brain injury.

**Change in Family Relationships**

As a result of family role changes, relationships between family members also change. Parents with an ABI may experience extreme hostility towards their children or even compete with their children for the attention of the other, non-injured parent (Elbaum, 2007b; Florian & Katz, 1991). This is a behaviour that has most commonly been seen in fathers, where fathers increase their demands on the caregiver as their children’s demands on the caregiver increase (Florian & Katz, 1991). Unfortunately, this hostility and competitiveness becomes not only draining for the caregiver, but also confusing and distressing for the children who quickly learn to decrease their demands on their parents (Elbaum, 2007b; Florian & Katz, 1991; Rolland, 1999). Younger children do not always understand what has happened to their parent, as they are often sheltered from the same information that the rest of the family may receive (Junqué et al., 1997). Therefore, many younger children living with a parent with an ABI frequently disconnect from their parents in an effort to both protect themselves as well as their parents (Butera-Prinzi & Perlesz, 2004).

Conversely, the caregiver may dedicate more of his or her time and energy towards the children of the family in an effort to ease their adjustment (Charles et al., 2004). Therefore, as the father with the ABI continues to feel rejected, he may distance himself from the rest of the family and exhibit more aggression and frustration than usual (Charles et al., 2004). Thus, the combination of his reaction, his sense of rejection, and the continued care for their children may drive both parents apart (Charles et al., 2004).
The change in the family dynamics and relationships without appropriate support and adaptation has been identified as the primary contributor to overall familial relationship break-down and disintegration (Webster et al., 1999).

The numerous changes that impact individual family members are unclear as it depends primarily on the pre-injury family functioning. However, research has also indicated that one of the primary predictors for family adaptation, family functioning, and marital stability is the level of the primary caregiver’s stress and distress (Arango-Lasprilla, et al., 2008; Carnes & Quinn, 2005; Douglas & Spellacy, 1996; Gan, Campbell, Gemeinhardt, & McFadden, 2006). The primary caregiver suddenly becomes the primary source of support for the entire family regardless of which family member acquires the brain injury as it is exceptionally rare for two caregivers to be able to provide equal amounts of support to the family member (Orto & Power, 2000). As Rolland (1994) explained, if the majority of the roles and responsibilities are placed upon one family member, then that family member may become resentful and overwhelmed with the increased levels of stress. The caregiver also provides for other family members in need of support, sometimes, at the expense of his or her own well-being (Orto & Power, 2000). As the caregiver continues to provide care to all family members, caregiver stress and burnout becomes a concern, as ABI is a long-term condition that will continuously impact the family (Arango-Lasprilla, et al., 2008; Orto & Power, 2000).

The literature clearly states that the more distressed the caregiver becomes, the more difficulties the family will experience while adjusting to a family member’s ABI (Arango-Lasprilla, et al., 2008; Douglas & Spellacy, 1996). Therefore, caregivers are frequently provided with additional support and are typically informed of the resources
available to them. Although older children or adolescents demonstrate unique needs given their “in-between status” as both children with needs and caregivers providing support (Elbaum, 2007b), it is unclear how these needs can be met while they are addressing the changes within their family, their family member, and themselves.

**Adolescence and Emerging Adulthood**

Adolescence and emerging adulthood are two transitional periods in life that are the result of biological, psychological, and social influences. Adolescence typically starts at approximately 12 to 13 years of age and continues into approximately 17 years of age (Carr, 1999; Erikson, 1968). Because of individual differences in development, these age ranges can vary. Adolescence is characterized by multiple changes occurring in the individual including but not limited to physical, biological, psychological, emotional, social, and cultural changes. As a result, adolescence can be viewed as a tumultuous time in a child’s life as he or she adjusts to multiple and consecutive changes in a short time period. Therefore, there is considerable research literature conceiving of adolescent development as a time of chaos, uncertainty, and “storm and stress” (Arnett, 1999; Steinberg & Morris, 2001). In reality, most adolescents transition to fully functional, competent adults (Arnett, 2006; Steinberg & Morris, 2001).

More recently, researchers have acknowledged that adolescence does not simply end, but rather many adolescents enter into an emerging adult phase where they continue to explore their identity and the meaning of adulthood (Arnett, 2006). This new phase is believed to start at approximately 18 years of age, ending at approximately 22 to 25 years of age (Arnett, 2006). Again, because of individual differences in development as well as culture, the age range of this phase varies. Emerging adulthood has recently been
researched to better understand the problematic as well as normative processes, experiences, and resiliencies of this transitional period of life (Arnett, 2006; Asberg, Bowers, Renk, & McKinney, 2008; Berzonsky & Kuk, 2000; Masten, Obradovic, & Burt, 2006; Sasaki & Yamasaki, 2007).

Despite the emphasis on atypical or non-normative development in adolescence and emerging adulthood, it is important to note that understanding abnormality also helps us identify normality and resilience. Without the challenges, we may not know the impact and power of personal strength and resilience in surviving a traumatic event or crisis in adolescence or emerging adulthood. Therefore, the literature presented in this section is a combination of research focusing on both normal and abnormal adolescent development. The following sections will describe adolescence as a transitional period, adolescent resilience and coping, emerging adulthood as a second transitional period, and the impact of and adjustment to trauma and family crises.

**Adolescence as a Transitional Life Period**

Adolescence is described as critical period in any North American person’s life as it is a period of intense growth, learning, and experimentation (Armstrong, 2007; Steinberg, 2005). Adolescence is a time of major biological, psychological, and cognitive changes (Carr, 1999). Biologically, adolescents experience puberty giving them adult-like bodies and functions, yet psychologically, adolescents are still very much like children. Their brains continue to develop at an accelerated rate, but now, adolescents are better able to make decisions, courtesy of the developing pre-frontal cortex (Steinberg, 2005). However, by virtue of the developing pre-frontal cortex, many adolescents lack the capability to anticipate the consequences of their immediate actions.
without experimentation. This is similar to a trial and error approach. Therefore, adolescents have the capability to be incredibly innovative, creative, and ingenious in ways that adults would never have thought of before (Steinberg, 2005).

This same function is what allows adolescents to make choices that are potentially harmful, life-threatening, and impulsive. As adolescents learn that certain choices lead to negative consequences, they become better at predicting various outcomes and developing skills to manage those outcomes (Compas, 2004; Rutter, 1990). Individuals’ experiences during adolescence can either enhance their adjustment in adulthood or hinder it as they carry their experiences into adulthood (Arnett, 2006; Erikson, 1968). One key contributor to the impact of the adolescent experience is the adolescent’s ability, freedom, and willingness to explore his or her identity in an attempt to find his or her place in the world (Erikson, 1968; Steinberg, 2005).

**Identity, parent-child relationship, and parenting style.** Research indicates that identity formation is critical to adult adjustment and psychosocial functioning in adulthood because identity will carry forward into the adult years, thus impacting the sense of self and the way individuals will conduct themselves in society (Beyers & Goossens, 2008; Cait, 2008; Smits et al., 2008). As such, considerable research has explored adolescent identity formation to inform how this process can be better supported.

In the Psychosocial Theory of Development, Erik Erikson (1968) described an adolescent identity crisis that fosters or hinders development as well as the transition to adulthood. Erikson (1968) believed that all psychosocial development hinges on the individual’s ability to overcome a series of challenges and crises across the lifespan. In
the case of adolescents, they are confronted with forming their identity or developing a
diffused identity (i.e., an identity that is incoherent, disjointed, and incomplete; Erikson,
1968). As such, adolescents establish their unique identity encompassing their
occupational, sexual, and ideological selves through a process of exploration. Erikson
(1968) believed that adolescents must experience a *time-out* called psychosocial
moratorium to allow themselves the time to explore their identity without activities that
could restrict their self-discovery pursuits. During the psychosocial moratorium, Erikson
(1968) believed that adolescents frequently experiment with various roles to determine
what roles and identities best fit with their sense of self.

As such, adolescents make a series of decisions based on their identity exploration
and role experimentation to ultimately determine what kind of adult they want to be, what
kind of adult they could be, and what that role and identity could look like. Adolescents
begin to contemplate what it would be like to be completely in charge of their actions and
choices including managing both positive and negative outcomes (Cumsille, Darling,
Flaherty, & Martinez, 2009). However, this exploration depends highly on the
satisfaction and quality of the parent-child relationship (Faber, Edwards, Bauer, &
Wetchler, 2003).

The parent-child relationship is critical in adolescent identity development and
adult adjustment due to the ongoing influence of the parent (Beyers & Goossens, 2008;
Levitt, Silver, & Santos, 2007). Levitt et al. (2007) found that a supportive relationship
between adolescents and their mothers predicted positive adjustment to adult life in
comparison to an unsupportive relationship. Furthermore, adolescents’ satisfaction with
the relationship with their mothers was predictive of a better transitional experience in
comparison to those who were dissatisfied with their parent-child relationship (Levitt et al., 2007), suggesting that relationship quality (i.e., closeness, supportiveness, warmth, secure attachment) is imperative to adult development. The authors suggested that this was because the adolescents felt they could approach their parent for guidance easily.

Other research has suggested that perceived satisfaction and quality of the parent-child relationship also predicted better coping, better psychological adjustment, better quality friendships, and less anti-social behaviours in adolescents (Cavanagh, 2008; Ciairano, Rabaglietti, Beyers, Rogerro, & Bonino, 2007; Faber, et al., 2003). With a supportive, caring, and warm relationship, parents are in a better position to directly (e.g., encouraging identity exploration) and indirectly (e.g., modelling) guide their adolescents through the transition to adulthood as needed or as requested (Levitt et al., 2007). However, as per North American cultural values of independence and autonomy, adolescents tend to request little guidance throughout their transition (Smits et al., 2008).

As adolescents struggle to independently define adulthood and resolve their adolescent identity crises, they attempt to distance themselves from their parents hoping only to rely on themselves like any other, highly valued, independent adult (Armstrong, 2007). Yet, it has been found that adolescents continue to need support and guidance to ensure that they are prepared for adulthood (Beyers & Goossens, 2008). To foster this independence and respect adolescents’ autonomy, parents must balance treating their children as “children” and providing them with the freedom to explore their identity (Cumsille et al., 2009). As such, parents have a critical role in supporting their adolescents’ transition into adulthood. How the parent supports the adolescent’s self-
exploration will depend on the parents’ parenting style, as this would impact the adolescent’s sense of freedom to explore his or her identity (Faber et al., 2003).

Faber et al. (2003) found that adolescents who had authoritative parents (described as warm but firm parents) were the most successful in taking the opportunity to explore and develop their identity during their psychosocial moratorium. As such, these adolescents were more likely to have a positive transitional experience and be well-adjusted in adulthood. In addition, Faber and colleagues also found that adolescents with authoritarian parents (described as strict disciplinarians) were less successful in discovering their own identity and resolving the adolescent identity crisis. This is problematic because, as Erikson (1968) explained, when individuals are unable to resolve the identity crisis, their development and maturity is delayed, thus stunting their overall adult development.

In addition to parenting styles, research has shown that perceived parental authority continues to have an influence on adolescent identity development, adult adjustment, and relationships across the lifespan (Carr, 1999; Cumsille et al., 2009; Levitt et al., 2007). Cumsille et al. (2009) found that the amount of perceived parental authority begins to wane in some areas such as how the adolescent should spend their free time, yet remains constant in other areas such as drug and alcohol use (Cumsille et al., 2009). Therefore, it seems that adolescents still rely on their parents for appropriate or inappropriate behaviours as they explore their identity, indirectly seeking guidance and approval. Thus, Cumsille et al. (2009) supports the argument that parents continue to act as role models as well as a critical source of guidance as the adolescent matures and transitions into adulthood.
**Familial stress.** There is evidence that under familial stress, some adolescents may stop listening to their adult guides entirely (i.e., parents, guardians, teachers, mentors, etc.) and start listening to their peers exclusively, thus, increasing the influence of their peers (Ciairano et al., 2007). This is problematic for numerous reasons, but the primary reason is that other adolescents are experiencing the same changes and confusion (Steinberg & Morris, 2001). Therefore, this may be a case of the blind leading the blind, which can be destructive given the right circumstances. As Carr (1999) explained, if adolescents associate with deviant peer groups that may encourage substance abuse, criminal behaviour, problem-behaviours, or other unhelpful coping strategies, adolescents are more likely to increase their risk of a maladjusted adulthood that may result in poor overall wellbeing.

By combining the psychosocial factors with the biological changes and the, occasionally, impulsive decision-making (Armstrong, 2007; Steinberg, 2005), adolescents can potentially make decisions that could forever impact their life without recognizing the long-term results. Given the influence of parents, it is clear that either losing a parent or experiencing a similar loss where the parent is no longer capable of being a source of guidance could have detrimental effects as the adolescent no longer has his or her primary source for direct or indirect guidance. For some adolescents, this could mean deciding to experiment with drugs, alcohol, tobacco, and sex, while for others it could mean gaining incredible focus in pursuing a dream career such as being a rock star or actor (Armstrong, 2007; Compas, 2004; Liedenberg & Ungar, 2008). These choices all depend on individual resiliency.
With the creativity of children and the capacity for adult-like decision-making, adolescents are truly betwixt and between (Turner, 2005). Depending on their unique resiliency factors and individual circumstances, adolescents may either strive towards their potential or gain developmental problems such as psychopathology, identity diffusion, addictions, or behavioural concerns that could continue to haunt them well into their adulthood (Rutter, 1990). It seems that parental relationship quality, satisfaction, and style of parenting can significantly contribute to adolescent resilience when encountering significantly stressful life events (Carr, 1999; Compas, 2004).

**Resilience and Coping**

Although the literature may describe adolescence as a stressful and vulnerable time period, most adolescents become fully adjusted adults. How do adolescents manage to successfully transition to adulthood despite the many challenges and stressors they may encounter? What is the difference between the adolescent who transitions into a well-adjusted adult and the adolescent who struggles into adulthood? Researchers have concluded that risk and resilience factors contribute to adolescents’ successful transition to adulthood (Baldwin, Baldwin, & Cole, 1990; Compas, 2004; Liedenberg & Ungar, 2008; Rutter, 1990). Furthermore, resilience factors tend to remain stable, fluctuate, or dissipate over the individual’s lifetime making resilience a useful concept when children and adults alike encounter adversity (Flach, 1988). Research has found that many factors contributing to resilience, such as coping styles, are developed and strengthened in adolescence (Masten et al., 2006) because of the challenges the adolescent encounters. This is also due to the adolescent’s trial and error process mentioned earlier in the chapter.
Resilience has been described as an individual’s or group’s response to risk factors which can lead to adaptation and adjustment despite adversity and/or trauma (Compas, 2004; Liedenberg & Ungar, 2008; Rutter, 1990). Resilience is composed of two important concepts that influence each other: protective factors and risk factors. Protective factors are mechanisms or processes that can offset the negative impact of stressors or risk factors that could lead to a negative outcome (Rutter, 1990). Conversely, risk factors or vulnerability mechanisms are described as elements that increase the probability of a negative outcome for an individual or group of people (Compas, 2004; Rutter, 1990).

Protective and risk factors can be the result of internal mechanisms, such as positive self-esteem, cynicism, optimism, self-determination, hope, or other mechanisms that are internally driven (Baldwin et al., 1990; Rutter, 1990). Protective and risk factors can also be the result of external or environmental mechanisms, such as parental support, peer support, SES, poverty, or other systemic and environmental factors (Compas, 2004). Interestingly, Rutter (1990) and Compas (2004) emphasize that any internal or external mechanism can be a risk factor as well as a protective factor depending on the circumstances. For example, stubbornness may be beneficial for individuals pursuing a goal, yet that same trait can also become a risk factor, as individuals may not acknowledge when the goal is no longer achievable. Conceptually, resilience is the interplay between protective and risk factors that continuously shift and develop across the lifespan (Flach, 1988; Rutter, 1990). When protective factors are not sufficiently strong or effective to offset the risk factors, the effects may negatively impact the individual’s development (Armstrong, 2007; Compas, 2004).
**Coping strategies.** One important contributor to resilience is the individual’s coping strategies as it impacts how the individual manages his or her risk factors, both internally and externally. To better understand how coping can impact resilience, I will discuss Lazarus and Folkman’s (1984) transactional stress model. This complex stress model outlined how a person may appraise his or her personal resources such as perceived time commitment, beliefs, and skills, in comparison to the perceived demands of the stressor (Lazarus & Folkman, 1984). If the perceived demands of the stressors exceed the perceived personal resources or one’s perceived ability to cope, then the individual will experience feelings of stress. As stressful feelings continue to increase, Lazarus and Folkman (1984) state that each person must develop ways to cope with his or her stress so he or she can continue to function efficiently.

Lazarus and Folkman (1984) categorized the various ways individuals cope with stress into two coping styles: problem-focused coping and emotion-focused coping. Problem-focused coping occurs when individuals focus on eliminating the stressor or problem itself to reduce their feelings of stress. Lazarus and Folkman stated that this is typically the most effective strategy, but it is only successful if the person can realistically eliminate the problem creating the stressful feelings. For example, studying for an exam can relieve feelings of stress because the individual is actively engaging in eliminating the source of the stress (i.e., feeling unprepared for an exam).

Emotion-focused coping occurs when individuals attempt to eliminate their feelings of stress using other means such as venting, social support, and distraction or avoidance of the problem itself (Lazarus & Folkman, 1984). This strategy is effective in managing the feelings of stress, but it does not do anything to eliminate the source of the
stressed. Therefore, this strategy has typically been viewed as less helpful than problem-focused coping. However, this strategy is most effective when individuals are not able to do anything about the problem itself and can only manage the feelings. It is not helpful when the individual can eliminate the source of stress but chooses to only manage the emotional impact of stressful events (Sasaki & Yamasaki, 2007). Other authors have identified other strategies as well as developed other categories of coping styles (Carver, Scheier, & Weintraub, 1989; DeLongis & Holtzman, 2005), but these two larger categories continue to be included in most coping styles research studies.

Because coping strategies are dependent upon the appraisal of the stressor as well as personal resources, coping has become an integral part of the resilience literature which also considers the individual’s resources that could act as both a protective and risk factor (Compas, 2004; Flach, 1988). Recently, Compas (2004) proposed a model describing how stress, appraisal, coping, and resilience are connected in adolescent development, adding another element to understanding resilience in adolescents. Compas explained that adolescents’ appraisal of stressful events impact the adolescent’s coping strategy which then can become a risk or protective factor. In other words, if an adolescent chooses to cope with a stressful event within the family by escaping into drug use, this, in turn, increases his or her risk and vulnerability to traumatic and potentially negative outcomes. In this case, the coping strategy becomes the risk factor. However, if an adolescent chooses to immerse him- or herself in a sport or extra-curricular activity, this can become a coping strategy that can protect the adolescent while encouraging adolescent development (Compas, 2004). As such, coping contributes to adolescents’ resilience depending on their choices and preferences in coping strategies.
Transition to Transition: Emerging Adulthood

Emerging adulthood is a recent addition to developmental theory and research. Emerging adulthood is a new transitional stage of life (i.e., aged 18 to 25 years) that has developed as a result of the changing context of being a young adult in North America. Young adults are pursuing higher education, feeling less financially secure, marrying later in life, and having children later in life in comparison to adults from 50 years ago (Arnett, 2006). Some research has suggested that this is the result of poor identity formation in adolescence (as cited in Berzonsky & Kuk, 2000), but the majority of research has found that emerging adulthood is simply the result of cultural circumstances (Arnett, 2006; Luyckx, Schwarts, Goossens, Soenens, & Beyers, 2008). As a result, it seems that North American youth have an extended adolescence (Arnett, 2006) to become better equipped to manage and meet societal demands, yet this period is distinct from adolescence.

To better understand this transition, I will discuss the Integrated Transition Model (Goodman et al., 2006) and demonstrate how this model is applied to emerging adults based on the existing literature. The Integrated Transition Model is an adult development model that integrates earlier theories explaining adult transition and also reflects the individual’s ability to integrate the life event or non-event into his or her identity (Goodman et al., 2006). All transitional experiences are believed to be triggered by an event or non-event that results in change in the individual’s life (Goodman et al., 2006). This trigger results in an adult experiencing three non-linear phases: Moving In, Moving Through, and Moving Out. It is important to note that these phases do not need to occur in the sequence in which I will discuss them here.
Moving in is characterized by individuals adopting new roles, relationships, assumptions, and routines (Goodman et al., 2006). This entails individuals becoming more familiar with the expectations, rules, and responsibilities resulting from the change in circumstances. While individuals are becoming more familiar with their new circumstances in this phase, they will often reflect on what their circumstances were and the changes that had occurred. This is called the identity hang-over as individuals struggle to accept a new identity while leaving their old identity behind (Goodman et al., 2006).

Moving through is characterized as being between two circumstances (Goodman et al., 2006). This occurs when individuals have learned new roles, responsibilities, assumptions, routines, and relationships. However, they are still torn between what life was like before the trigger, and what life was like after the trigger. This is characterized by uncertainty, confusion, and potentially a feeling of emptiness as they attempt to fill their new lives with new meaning. This period of liminality results in a fluctuation of hope and spirituality as individuals struggle to understand why their circumstances changed and how to manage the change.

Moving out is characterized by a sense of finality and acceptance that life will never be the same (Goodman et al., 2006). Individuals disengage from their pre-transition roles and identities and begin to reconstruct a new sense of self that allows for the change in circumstances. This stage can include a period of grief where individuals mourn the loss of their old lives while accepting their new lives. Essentially, individuals begin to integrate the transitional events into their identities as well as other areas of their
lives as they let go of what was and accept what is. This integration includes combining elements of the “old self” with elements of the “new self.”

As a new transitional period, emerging adulthood is being investigated in the research literature to better understand the nature of this new developmental phase. Arnett (2006) suggested that emerging adulthood is characterized by five features. The features are (a) identity exploration, (b) instability, (c) self-focus, (d) feeling in-between, and (e) possibility. These features seem to coincide with the adult transition model described by Goodman et al. (2006).

**Identity exploration.** Originally, identity exploration was thought to be something that was unique to adolescence (Arnett, 2006; Luyckx et al., 2008). As stated earlier, Erikson (1968) believed that if adolescents missed their milestones of identity formation by not forming a stable identity, they would likely encounter difficulties throughout adulthood. Newer research has revealed that identity develops over a lifetime rather than only in adolescence (Armstrong, 2007; Arnett, 2006; Berzonsky & Kuk, 2000; Masten et al., 2006; Steinberg & Morris, 2001). Identity development may begin in adolescence, but it continues into emerging adulthood as young adults search for what they want in life, future romantic partners, and careers (Arnett, 2006). This identity development is characteristic of the moving in phase, where young adults are attempting to adopt new roles that they believe characterize them as adults (Goodman et al., 2006).

**Instability.** Arnett (2006) identified this feature based on the multiple changes in living arrangements, job options, romantic partners, and friendships. These changes demonstrate how emerging adults explore and adjust to frequent changes in their lives. Emerging adults experience financial insecurity, residential instability, romantic
uncertainty, and career ambiguity (Arnett, 2006). Emerging adults hope for the best future, but experience considerable instability in exploring their possibilities and potential (Armstrong, 2007). This level of uncertainty and instability is characteristic of the moving through phase as there is considerable confusion about how to combine “adult identity” with their existing identity (Goodman, et al., 2006).

**Self-Focused.** This third feature is typical of most emerging adults. Although to the outsider, emerging adults may be making many decisions out of self-centredness, the emerging adults only have themselves to consider in their decisions as they are free from many social obligations of the fully fledged adult (Armstrong, 2007; Arnett, 2006). This self-focus promotes the exploration of identity (Berzonsky & Kuk, 2000; Luyckx et al., 2008). This self-focus is yet another characteristic of the moving in phase due to the necessity of ongoing self-exploration. This is also where individuals start to separate themselves from their parents, and the parental influence has less of an impact on the individual’s identity formation.

**Feeling in-between.** Emerging adults often state that they do not “feel” like adults (Arnett, 2006; Berzonsky & Kuk, 2000). Arnett (2006) described how many emerging adults attempt to define adulthood for themselves to relieve the pressure of “being an adult.” Frequently, emerging adults will state that they think they are adults in some ways, while in other ways, they are still very much adolescents. This is likely due to the necessity to rely on their parents for many elements of their lives such as finances and career options. This sense of being in-between is characteristic of the moving through phase.
Possibility. Emerging adults are often optimistic about their future and hope that they can achieve the best for themselves (Arnett, 2006). Therefore, the opportunities seem endless for many emerging adults. This characteristic carries forward from adolescence where big dreams and goals were made, and as emerging adults, they make the steps to pursue their dreams (Armstrong, 2007). Furthermore, emerging adults are focused on developing and building this adult life while they remain in-between (Armstrong, 2007). It may seem like the emerging adult is ambitious and pursuing dreams. This is similar to the moving through phase in which the emerging adult hopes for an improved future, and takes on new adult roles with more expertise and comfort.

Emerging adults also explore possibilities by leaving their families of origin and exploring different and, potentially, more favourable adult lives (Arnett, 2006). This is especially true if individuals experience what they perceive as a negative family environment, such as family crises and trauma (Masten et al., 2006). However, this is entirely dependent on individual resiliency and relationships within the family. If the individual has few protective factors, it may be more difficult to leave a troubled family life if it is unhealthy for the individual (Masten et al., 2008). This is characteristic of the moving out phase where emerging adults accept the change and start to embrace it by leaving their families of origin, and also leaving parental influence with it.

It is clear that emerging adulthood is a transitional phase between adolescence and adulthood. However, because emerging adulthood is similar to adolescence and adulthood, a purely adult development model does not account for adolescent-like behaviours. For example, the self-focus characteristic of emerging adults is carried over from adolescence, but the integrated transition model developed by Goodman et al.
(2006) does not completely account for the impact of this self-focus. As a continuation of adolescent identity development, it is imperative to also consider the parental and familial influences on these individuals as they continue their journey to adulthood.

**Trauma and Family Crises**

Trauma is the result of experiencing an event that is (a) sudden, unexpected, or outside of normative experiences; (b) perceived as being beyond a person’s ability to meet the demands of the situation; and (c) disrupts the individual’s frame of reference and psychological needs (McCann & Pearlman, 1990a). Combined, these elements force individuals experiencing a traumatic event to reframe their understanding of the world around them in a way that allows for the occurrence of such an event (Baranowski, Gentry, & Schultz, 2011). However, problems arise when individuals are unable to successfully reframe their experience and continue living healthy lives (McCann & Pearlman, 1990a).

In adolescents, the symptoms of trauma can include behavioural, psychological, emotional, and cognitive problems (Cohen, Debingter, & Mannarino, 2006). However, it is important to note the immense variability in trauma symptoms, depending on the traumatic experience, the context of the experience, the systemic influences, and the unique resilience and protective factors of the individual (Baranowski et al., 2011; Cohen et al., 2006; Compas, 2004; Pine & Cohen, 2002). Behavioural symptoms can include avoidance of potential reminders of the trauma, escapism wherein the youth will attempt to run away from reminders of the trauma, and externalizing behaviours such as increased violence, aggression, and drug and alcohol use (Barkman et al., 2007; Cohen et al., 2006). Psychological symptoms can include higher incidence of psychopathology such
as depression, anxiety, and dissociative disorders (Cohen et al., 2006; Kieffer-Kristensen, Teasdale, & Bilenberg, 2011; Pine & Cohen, 2002). Emotional symptoms can include a heightened sense of fear, anger, injustice, and sadness (Cohen et al., 2006). Finally, cognitive symptoms can include decreased memory function and processing speeds (Cohen et al., 2006; Pine & Cohen, 2002). Interestingly, the cognitive symptoms can be extended to lapses in memory and inability to remember the trauma itself as well as certain events following the traumatic event. Given these vague symptoms, it is obvious how trauma can be misdiagnosed without a better understanding of the pre-cursing events and the context of the traumatic event (Taylor & Weems, 2009).

Because emerging adulthood is a relatively new phenomenon, there is very little research about how emerging adults manage trauma or family crises. It is suspected that they experience trauma symptoms similar to those of adolescents and adults (Masten et al., 2006). However, with more independence, it is possible that emerging adults may explore their possibilities for support outside of the family to help them overcome the traumatic experience. Furthermore, as legal adults, emerging adults may distance themselves from family crises or traumatic events within the family, which may help decrease the amount of familial stress emerging adults may experience (Sasaki & Yamasaki, 2007).

Adolescents may approach their parents in light of the trauma depending on their existing relationship with them (Levitt et al., 2007; Pine & Cohen, 2002). If the relationship is considered to be a strong, satisfactory relationship, adolescents are more likely to approach their parents to help guide them through the traumatic event (Levitt et al., 2007). However, if the trauma has occurred within the family increasing the level of
familial stress, adolescents are more likely to seek guidance from their same aged peers to cope with the event (Cavanagh, 2008). Trauma within the family may also be further complicated if adolescents do not experience the traumatic event directly. As such, adolescents as well as professionals may not recognize post-traumatic symptoms because of a lack of a traditionally defined traumatic event (Taylor & Weems, 2009).

**Vicarious traumatization.** Over the last 10 to 15 years, there has been considerable debate about how to define a traumatic event. If you conduct a quick search in the research literature about what is considered a traumatic event during adolescence or emerging adulthood, you would often find topics focused on abuse, neglect, war, terrorism, or the sudden and inexplicable death of a loved one (Cohen et al., 2006; Pines & Cohen, 2002; Taylor & Weems, 2009). You may not expect that a trauma occurring to a family member would also potentially traumatize the rest of the family. However, there is increasing evidence suggesting that adolescents and children are more likely to be traumatized by exposure to the event regardless of their personal experience of the event itself (Kelly & Ward, 2011; Taylor & Weems, 2009).

Traumatization resulting from another individual’s experience of trauma is called vicarious traumatization – a term originally used to describe the traumatization of helpers who have worked with clients with trauma (McCann & Pearlman, 1990b). However, it is likely that vicarious traumatization could also impact other individuals who are close to the individual who was traumatized such as family members (Kelly & Ward, 2011). In a close and supportive role, family members may also experience vicarious traumatization resulting in post-traumatic symptoms (Kieffer-Kristensen et al., 2011; Kelly & Ward, 2011). As a newly researched phenomenon, evidence of vicarious traumatization within
the family expands the definition of trauma to include not only the direct experience of a traumatic event, but also the indirect experiences of trauma (Kelly & Ward, 2011).

**A changing definition of trauma.** Recent research suggests that the traditional definition of trauma is limited due to the immense variability in the traumatic events (Kelly & Ward, 2011), the subjective definition of traumatic events (Taylor & Weems, 2009), and the post-traumatic symptoms (Kieffer-Kristensen et al., 2011; Taylor & Weems, 2009). Taylor and Weems (2009) proposed including developmental definitions of trauma because trauma is a phenomenon experienced at all developmental stages with various expressions of post-traumatic symptoms. Therefore, what would be traumatizing as a child may not be considered traumatizing in adolescence or adulthood (Taylor & Weems, 2009). Taylor and Weems indicated that the current classification of trauma limits what can be considered trauma. As a result, many individuals with trauma-related symptoms may be ignored because the event may not be “traumatic enough”.

Kieffer-Kristensen et al. (2011) found that 46% of the children of parents with ABIs sampled exhibited post-traumatic stress symptoms after their parent had acquired a brain injury. This finding supports that children of parents who have acquired a brain injury are at an increased risk of vicarious traumatization because of the unique experience of ambiguous loss as well as the process of adjusting to the parental ABI. Therefore, youth are more likely to experience more difficulties overcoming this trauma given the absence of a clear traumatic event and a clear loss. Without appropriate support and education, vicarious traumatization combined with normal and increased familial stress contributes to youth vulnerability, thus increasing the likelihood that adolescents and emerging adults may become maladjusted (Kieffer-Kristensen et al., 2011).
Ambiguous Loss

The literature concerning family members living with an individual with an ABI frequently mentions the experience of grief for the individual with the ABI. Most authors indicated that in light of the ambiguity and uncertainty of any type of brain injury, it follows that individuals close to the person with the ABI will experience a sense of loss (Boss, Roos, & Harris, 2011; Butera-Prinzi & Perlesz, 2004; Landau & Hissett, 2008). This is in reaction to the sense that a person with an ABI is “a different person” or has a different personality as a result of the multiple changes from the ABI (Yeates et al., 2008). This kind of loss is appropriately called ambiguous loss, where the loss itself is unclear and uncertain.

Boss et al. (2011) proposed two types of ambiguous loss called physical ambiguous loss and psychological ambiguous loss. Physical ambiguous loss encompasses the physical loss of the loved one without proof of the loved one’s death. For example, children who are kidnapped may be psychologically present within the family while not physically present. This kind of loss is particularly unclear as those experiencing grief have difficulties moving forward without the certainty of the death or permanent loss. The second kind of loss is psychological ambiguous loss: the experience of losing a loved one who is still physically present. For example, an individual with Alzheimer’s disease is physically present, but psychologically changed from the person he or she was before the diagnosis. As such, loved ones grieve the loss of who the individual was. Psychological ambiguous loss is the most frequently reported type of loss by family members adjusting to an individual with an ABI (Boss et al., 2011; Elbaum, 2007b; Landau & Hissett, 2008; Orto & Power, 2000).
Ambiguous loss has been identified as a somewhat more complicated and difficult process (Boss et al., 2011) because of the inherent uncertainty that defines this unique type of loss. Adolescents who experience loss may experience some difficulties in effectively processing it and coping with it (Servati-Seib & Taub, 2010). This is because adolescents are believed to have dualistic thinking, which can be described as thinking on two different polarities (e.g., something is black or something is white, there is no grey). As such, individuals with dualistic thinking are more likely to seek answers to many questions (i.e., Why him or her? Why my family? How do I get through this?) from authorities such as religious leaders or established adults (Servati-Seib & Taub, 2010). Furthermore, individuals with dualistic thinking are also more likely to struggle with managing their sense of loss while attempting to reconstruct and restore their life without the loved one (Servati-Seib & Taub, 2010), thus delaying their progress and adjustment.

Ambiguous loss is frequently missed by counselling practitioners because it does not fit with the conventional ideas of loss (Winokuer & Harris, 2012). As such, this unique form of loss goes unacknowledged and unnamed for many individuals (Boss et al., 2011). This is problematic as the individual experiencing ambiguous loss may exhibit grief-like symptoms without calling it grief, and thus, potentially invalidating their own experiences (Boss et al., 2011). Boss (2007) indicated that ambiguous loss encompasses many complex emotions, which can include guilt for feeling a sense of loss. This applies to both types of ambiguous loss.

In the case of physical ambiguous loss, an individual may feel guilty for his or her feelings of grief when he or she has not received confirmation of the loss of the individual. As such, the individual may feel he or she has given up hope for the
individual. In the case of psychological ambiguous loss, an individual may feel guilty for his or her feelings of grief when the individual is still physically present. Because of these feelings of guilt, individuals experiencing ambiguous loss may not want to acknowledge their sense of loss or call it loss without the external validation of the loss itself (Boss et al., 2011).

Adolescents and emerging adults are less likely to describe their experiences with their peers or friends from fear of having their experiences invalidated (Boss, 2007; Boss et al., 2011; Servati-Seib & Taub, 2010; Winokuer & Harris, 2012). As such, adolescents and emerging adults are more at risk of ignoring, and thus, not effectively processing their ambiguous loss (Servati-Seib & Taub, 2010). Given adolescents’ hesitation to seek support from their family during times of familial stress and their likelihood of not disclosing their ambiguous loss to their peers, it seems that adolescents are at an increased risk of being unsupported throughout their self-search and identity development when their family is impacted by an ABI that induces both increased familial stress as well as ambiguous loss.

**Summary and Significance**

An ABI impacts multiple areas of an individual’s life including physical, behavioural, cognitive, psychological, and social functioning. As such, an individual with an ABI may seem like a different person after the injury due to the combination of all the changes that occur (Yeates et al., 2009). Given that families have been found to be the primary sources of supports for individuals with ABIs (Kreutzer et al., 2009), it is critical that families are strong enough to withstand the stress and strain on their familial relationships as they attempt to support their family member’s recovery. Some families
struggle with this adaptation process while others seem to manage adequately. The difference between families is believed to be due to family resilience as families are expected to support the individual with an ABI, adjust the family system, reorganize the family structure, and continue to meet individual needs (Rolland, 1994; Walsh, 2003). While some families are successful in adjusting to these changes, other families witness relationship disintegration (Webster et al., 1996).

Evidence suggests that adolescents and emerging adults who also require familial support as they transition to adulthood are considered to be at an increased risk of mental health and psychosocial developmental concerns when their parents acquire a brain injury. This is because adolescents continue to rely on their parents for guidance as they explore their identity and determine what they want their adulthood to look like (Beyers & Goossens, 2008; Cavanagh, 2008; Faber et al., 2003; Levitt et al., 2007; Sasaki & Yamasaki, 2007; Smits et al., 2008). Although adolescents and emerging adults may have their own unique protective and risk factors, research suggests that many adolescents may become more at risk as a result of an ABI occurring in their families due to the increase in familial stress (Cavanagh, 2008; Faber et al., 2003) and little validation of and support for their potential vicarious traumatization (Kieffer-Kristensen et al., 2011) and ambiguous loss (Boss, 2007).

Although adolescent children and emerging adults are discussed in passing in the research literature about a family member with an ABI, there are few studies that focus specifically on the experience of the children of parents with ABI. It seems that there are many potentially negative and detrimental outcomes that can result from living with a parent with an ABI, yet the extent of these negative outcomes is somewhat unclear. For
example, it is unclear if the adolescents and emerging adults attribute their negative outcomes to living with their parents with ABIs.

From an objective and outsider perspective, the research literature suggests that children of parents with ABIs are at an increased risk of maladjustment and problematic development due to multiple reasons attributable to the influence of a parent with an ABI. Although objective data are critical in understanding some of the issues and outcomes associated with living with a parent with an ABI, the data do not provide us with an understanding of what adolescents and emerging adults believe they need to be supported during this experience. By neglecting the voices of these children, we ignore an important piece of the puzzle in understanding this unique experience.

Few research studies consider the subjective experience of living with a parent with an ABI from the perspective of the adolescent or emerging adult. They have not been asked “What is it like for you to live with a parent with an ABI?” This is a question that remains unanswered from the unique perspective of the adolescent and emerging adult and is the main focus of the current study. This question is significant because it can provide critical insider information about how counselling psychologists and other practitioners can better support these adolescents and emerging adults while addressing their unique needs. We need to better understand the story told by these adolescents and emerging adult children to inform research and practice.
CHAPTER THREE: METHODOLOGY

In this chapter, I will discuss the methodology I used to investigate the research question: What is it like for adolescents and emergent adult children to grow up living with a parent with an acquired brain injury? More specifically, I will discuss my reasoning for choosing a qualitative methodology and justify my choice to use heuristic inquiry to explore the research question. I will then discuss the concepts and phases of heuristic inquiry to explain the methodology itself as it is outlined in the research literature. In the process of outlining heuristic inquiry, I will share my specific process and procedure for collecting and analyzing the data. Finally, I will discuss the necessary steps I took to ensure the quality of this research.

A Qualitative Study

I chose to investigate the research question using qualitative methodology. Qualitative research has been described by Creswell (2013) as a research process that begins with assumptions and the use of interpretive or theoretical frameworks to inform the study of a research topic or problem exploring and addressing the meaning that individuals or groups associate with the problem. Creswell explained further that unique to all qualitative research is the natural and sensitive way data are collected where the researcher is mindful of the people and places under study. Earlier definitions discussed by McGrath and Johnson (2003) define qualitative research in contrast to quantitative research to help readers become more familiar with qualitative methodology and the philosophical underpinnings and assumptions of all qualitative research.

While positivist (and typically, quantitative) researchers recommend that researchers remain objective to generalize their data, qualitative researchers are
encouraged to embrace their subjectivity because of an underlying assumption that objectivity is only a part of the Truth being investigated (McGrath & Johnson, 2003). It is clear in many qualitative theoretical approaches that the goal is not to understand the ultimate truth, but to understand and compose a complex, yet full, picture of the problem being studied given a certain set of circumstances (Creswell, 2013). Qualitative research is not designed to seek the ultimate truth. Rather, it is designed to understand the meaning of the problem under study, and how individuals make meaning while experiencing the problem (Sela-Smith, 2002). Therefore, it is acceptable for researchers to embrace their interpretation as subjective and reflective of their personal experiences with the data. Although the level of subjectivity and reflexivity varies for each qualitative method, it is crucial for all qualitative researchers to be prepared to reflect on their experiences as researchers, their interactions with the participants, and the knowledge and data they have accumulated during their research (McGrath & Johnson, 2003).

I chose to address the research question using qualitative methodology because of the nature of the question. The experience of adolescents who have lived with a parent with a brain injury is a new area of research. Therefore, further exploration of it is needed to generate more specific questions about this experience. Creswell (2013) explained that a qualitative method is typically most effective with exploratory studies where the researcher is not aware of what specific elements need to be investigated. Therefore, qualitative research is ideal for research questions that prompt open discussion about a problem (McGrath & Johnson, 2003). Given the nature of this research, qualitative methodology is the most appropriate because I needed to explore and discuss
this topic rather than measure it. I knew this topic was particularly complex, and thus it would be difficult to anticipate the results. Therefore, I needed a methodology that would allow for a broad research question prompting discussion.

Furthermore, I wanted to hear the voices of those individuals who were usually ignored in the rehabilitation process, counselling, and medical interventions with their parents who have acquired an ABI (Butera-Prinzi & Perlesz, 2004; Junque et al., 1997). As demonstrated in the literature review, a lack of research literature discussing the subjective experience of adolescents and emerging adults who have lived with a parent with an ABI suggests that their story is often ignored in both research and practice. Their voices have not yet been heard in the academic literature, and they have not had the opportunity to express their needs, wants, hopes, and joys.

It is for these reasons that I have chosen to use heuristic inquiry as my methodology. I was first introduced to heuristic inquiry by my supervisor who suggested I use my personal experience to inform my research and activities. I began to explore other research studies using this same methodology and found that the personal benefit for both the researcher and the participants made this approach the most appealing. As described later in this chapter, my initial engagement with the topic and the methodology was a hesitant one, but I could not turn away from either. I decided that I was well suited to investigate this research topic, and that heuristic inquiry was the best way to investigate the topic. By using my personal experience and heuristic inquiry to guide my research, I would be able to understand and portray the complexity and richness that characterizes this experience.
Heuristic Inquiry

Heuristic inquiry is a qualitative research approach that is based on descriptive phenomenology (Moustakas, 1990; Sela-Smith, 2002). Descriptive phenomenology is a method of qualitative inquiry aimed at describing the essence of the lived experience of a phenomenon as the participants understand it (Wojnar & Swanson, 2007). It is believed that all individuals who have experienced the phenomenon describe common features that are essential to the lived experience (Lopez & Willis, 2004). These common features, also called the essences of the experience, are believed to reflect the true nature of the lived experience.

As such, descriptive phenomenology is used to describe the essence of the experience that is not impacted by the context of the experience (Wojnar & Swanson, 2007). The essence of an experience in descriptive phenomenology is the universal experience of all individuals who have had the experience with the phenomenon being studied. The essence of the experience can be tainted if the researcher allows personal bias or preconceived notions to influence his or her research procedure (Lopez & Willis, 2004). Therefore, researchers using descriptive phenomenology attempt to reduce or eliminate the influence of their personal preconceptions and biases about the phenomenon in a process called bracketing to get at the essence of the lived phenomenon. It is believed that bracketing is the only way to ensure the quality and scientific rigor of the research (Wojnar & Swanson, 2007).

Heuristic inquiry and descriptive phenomenology are similar in several ways. Firstly, both methodologies can be used to understand the lived experience of the phenomenon under study (Wojnar & Swanson, 2007). Both methodologies use methods
of inquiry in which the researcher engages in a one-to-one interaction with the participant
to freely discuss the experience (Moustakas, 1990; Wojnar & Swanson, 2007). As such,
researchers using descriptive phenomenology or heuristic inquiry must engage in an
ongoing interaction with the participant until the researcher believes he or she
understands the essence of the experience (Sela-Smith, 2002; Wojnar & Swanson, 2007).

Secondly, descriptive phenomenology and heuristic inquiry are used to reveal the
meaning of the experience discussed by the participants (Douglass & Moustakas, 1989;
Wojnar & Swanson, 2007). The meaning of the experience is critical to understanding
and reflecting on the essence of the experience according to the assumptions of both
methodologies. Further, Moustakas (1990) defined the essence of the experience
similarly to Husserl (as cited in Lopez & Willis, 2004) in that there is a core experience
unique to those who have experienced the phenomenon.

However, heuristic inquiry and descriptive phenomenology are different from
each other in two key areas. Firstly, the way in which the essence of the experience is
arrived at by the researcher is different for each methodology. Husserl (as cited in Lopez
& Willis, 2004) believed that reaching the essence of the experience can only be achieved
through bracketing whereby researchers set aside their personal experiences and biases to
prevent tainting the data. However, in heuristic inquiry, a shared meaning is created by
the researcher and the participants who share their experiences with each other during the
one-on-one interview as well as the member-checking process (Moustakas, 1990; Sela-
Smith, 2002). In this way, the meaning of the experience is co-constructed, allowing the
researcher to better understand the essence of the experience of the phenomenon beyond
his or her personal experiences. Although Moustakas (1990) believed that the essence of
the experience was also universal, the participants’ experiences cannot be separated from the context because it helps the researcher understand the similarities and differences.

Secondly, heuristic inquiry differs from descriptive phenomenology in that the researcher must include his or her personal experience with the phenomenon being investigated as part of the data set. Descriptive phenomenology is a method wherein researchers are unable to consider their subjective experiences because it is believed it will taint the essence of the experience (Husserl as cited in Lopez & Willis, 2004). Conversely, using heuristic inquiry, the researcher must first reflect upon his or her experience so that he or she can better identify the common features shared by the experiences of the participants and include his or her story in the data set. This reflective process, called self-dialogue, is critical to the process of heuristic inquiry because all research activities (i.e., literature review, recruitment, data collection, data analysis, and final reporting) are guided in part by the knowledge gained from the initial self-dialogue (Moustakas, 1990). As such, the researcher’s personal story is considered to be as important to include in the data as the personal stories of the participants.

**Heuristic Inquiry as a Methodology**

Heuristic inquiry is unique in that the researcher must have experienced the phenomenon being investigated in order to deepen the understanding of and insight into the phenomenon (Moustakas, 1990). The researcher must also be willing to include his or her story as data to contribute to the overall understanding of the phenomenon being investigated. This is because as the researcher and participants talk about the phenomenon and their personal experiences, they are both able to reflect upon and deepen their understanding of their own experiences. This exchange of information helps
the researcher to delve more deeply into experiences and ask more poignant questions during the interview, questions that the researcher may not have thought of before. As such, the researcher and the participants create a new meaning of both their experiences, which can promote healing and understanding for both the researcher and the participants (Etherington, 2004).

**Core concepts of heuristic inquiry.** To better understand heuristic inquiry, it is necessary to understand the seven core concepts that make this approach unique and reflect assumptions of the methodology (Moustakas, 1990). These consist of (a) identification with the focus of the inquiry, (b) self-dialogue, (c) tacit knowing, (d) intuition, (e) indwelling, (f) focusing, and (g) internal frame of reference. Moustakas (1990) believed that the researcher needs to utilize these concepts to successfully engage in heuristic inquiry. The core concepts are used throughout the course of the research process and some concepts may be more helpful to the researcher during certain phases of research than other concepts. I will explain each core concept here, followed by the six phases of heuristic research.

The first concept is the identification with the focus of the inquiry. This concept is used when researchers come to their research question as it tends to come from within or from their experiences (Moustakas, 1990). Researchers’ personal experience as well as initial curiosity about others’ experiences is what motivates researchers to explore the topic further, eventually developing a research inquiry. Moustakas (1990) believed that identification with the focus of inquiry was the reason many researchers are drawn towards certain topics (Sela-Smith, 2002). In recognizing their curiosity, researchers may
begin their investigation internally to identify the source of their interest and the need to clarify and closely examine the lived experience.

The second concept is called self-dialogue. Moustakas (1990) described this concept as a way in which researchers explore their experience of the phenomenon being investigated. As the research question being investigated stems from the self, researchers must learn to engage in a self-dialogue process, which can resemble a self-reflection process, to better understand certain aspects of the experience. Using self-dialogue, most researchers are able to consider and reflect upon experiences with multiple perspectives, angles, and conceptualizations to better comprehend the phenomenon. Moustakas stated that “one faces oneself and must be honest with oneself and one’s experience relevant to the question or problem” (p. 17), indicating that one must understand one’s personal experience of the phenomenon before one can begin to explore it.

The third concept is called tacit knowing. Tacit knowing is the foundation of all heuristic inquiry as it is used in every phase of the research process. Tacit knowledge is “where experience, feeling, and meaning join together to form both a picture of the world and a way to navigate that world” (Sela-Smith, 2002, p.60). Tacit knowledge has been described as the deep structure where information from a variety of experiences is collected and utilized to inform the perception, and therefore meaning making, of new experiences (Moustakas, 1990).

The fourth concept, called intuition, is described as the “bridge between the explicit and tacit knowledge” (Moustakas, 1990, p. 23). Using intuition, the researcher can access both explicit and tacit sources of knowledge to perceive and understand experiences. This can lead to immediate knowledge without using logic or reasoning to
make decisions. Researchers who use intuition gain the opportunity to perceive experiences as a whole rather than in several pieces as the researcher utilizes both key sources of knowledge (Moustakas, 1990). It is because of the intuition concept that researchers are able to discover patterns and meanings that can enhance the understanding of the phenomenon being studied that may not have been explored before.

The fifth concept is called indwelling. Indwelling refers to the process of researchers turning towards themselves to deepen and extend their understanding of the human experience (Moustakas, 1990). Researchers who use indwelling must be open and willing to focus entirely on the self and his or her experience with unwavering attention. As Douglass and Moustakas (1985) explained, a researcher cannot understand the unique qualities of the experience without dwelling on the experience itself and exploring the deeper meanings that each theme has for the researcher.

The sixth concept, called focusing, is the researcher’s ability to willingly explore the thoughts, feelings, and behaviours associated with the experience in their own time (Moustakas, 1990). There are always many elements of the experience that have not been made conscious to the researcher, and this concept helps the researcher to discover these new elements (Moustakas, 1990). In a relaxed state, a researcher can reflect on the elements of the experience to find any missing pieces that could inform a more comprehensive and rich understanding of the phenomenon being investigated.

The seventh and final concept, called the internal frame of reference, is essential to any heuristic inquiry (Moustakas, 1990). The internal frame of reference is the foundation of all perception of human experience (Moustakas, 1990). It is the culmination of lifetime learning, experiences, and knowledge used to understand the
outer world. Because the internal frame of reference shifts with each new experience, researchers must be willing to closely examine their experiences through their perceptions, thoughts, and feelings. By closely examining their personal experiences and reflecting upon their internal frame of reference, researchers are able to “validly provide portrayals of the experience” (Moustakas, 1990, p.26). Researchers who have experienced the phenomenon can reach a better understanding of the experience with more insight than a researcher who has not experienced the phenomenon because the internal frame of reference is informed by the experience itself.

**The phases of heuristic research.** There are six phases of heuristic research as described by Moustakas (1990). These are (a) initial engagement, (b) immersion, (c) incubation, (d) illumination, (e) explication, and (f) creative synthesis. Each phase evolves into the next without clear guidelines. Researchers cannot force the completion of one phase and the beginning of the next phase; it must happen naturally (Sela-Smith, 2002).

The first phase of heuristic research is the initial engagement with the topic, question, problem, or theme that represents a critical interest in an area of research (Douglass & Moustakas, 1985). This phase is typically paired with the concepts of identifying with the focus of inquiry, indwelling, and focus. In this phase, the researcher explores the topic to determine what exactly the researcher would like to investigate. Eventually, as the researcher explores the topic, she/he develops a research question to guide the research (Moustakas, 1990).

The second phase of research is immersion in the research topic and question. In this phase, the researcher lives, breathes, walks, and sleeps with a focus on the question
(Moustakas, 1990). In this process, researchers may use indwelling, internal frame of reference, self-dialogue, and intuition to guide their exploration of the question (Douglass & Moustakas, 1985). This second phase can include a literature review, data collection, and networking with the appropriate individuals. However, it is important to note that this phase typically looks different for different researchers and topics (Sela-Smith, 2002). The primary requirement is that the researchers feel they are in the midst of the question and on “intimate terms with the question – to live it and grow in knowledge and understanding of it” (Moustakas, 1990, p. 28).

The third phase of heuristic research is the incubation phase, during which researchers retreat from the intensity of the immersion phase (Moustakas, 1990). In this phase, the researcher withdraws from the focus on the question and the associated feelings, perceptions, dialogues, and thoughts. The researcher is no longer absorbed in the topic; rather the researcher is letting the information gathered in the immersion phase settle and become absorbed for further reflection. In this phase, researchers may use tacit knowledge and intuition to extend their current understanding of the information gathered beyond their immediate awareness (Moustakas, 1990). Researchers may seem to be taking a break from their data to help them return back to the information with a new understanding and different perspective.

The fourth phase of heuristic research is the phase of illumination. This phase has been said to “occur naturally when the researchers are open and receptive to tacit knowledge and intuition” (Moustakas, 1990, p. 29). Illumination is the phase of research that may result in a sudden breakthrough in understanding the data collected. In this phase, researchers may create clusters and categories of themes to reflect their
understanding of the phenomenon. Illumination typically results after the researcher has managed to reveal meanings that were previously hidden or undiscovered given their immense focus on the question. Researchers may use tacit knowing, intuition, self-dialogue, focus, and some indwelling to contribute to the reflective process. Researchers will need to organize and reorganize their data into multiple categories and clusters until they feel they have reached the most complete and representative reflection of all the participants experiences including their own.

The fifth phase emerges naturally from the fourth phase as the researcher is able to explicate the meanings within the phenomenon (Moustakas, 1990). The fifth phase is called explication. During this phase, the researcher explains in much more detail the themes, categories, and clusters as they relate to the research question. In essence, the researcher is explaining the meanings of the phenomenon in a way that represents, reflects, and honours each participant’s unique experience. As Moustakas explained, the purpose of explication is to “fully examine what has awakened in consciousness in order to understand its various layers of meaning” (p. 31). Explication then results in a deeper understanding of the experience of the phenomenon. Researchers may use all the core concepts of heuristic inquiry in an effort to make sense of all the information that has resulted in the explication phase.

The sixth and final phase of heuristic inquiry is the process of creative synthesis. In this phase, Moustakas (1990) emphasizes that researchers are familiar with their data, its qualities, the categories, themes, and the meaning of the phenomenon. A creative synthesis can only be achieved by using tacit knowledge and intuition to put all categories and core themes into a narrative depicting the experience of the researcher and
participants. The process of creative synthesis looks different for every researcher and every research question, and it is not restricted to narrative expression. The creative synthesis is intended to convey the complete experience of a phenomenon including its meaning, themes, perceptions, feelings, thoughts, beliefs, intuitions, and behaviours (Moustakas, 1990).

**My Procedure in Heuristic Inquiry**

As a fledgling qualitative researcher, heuristic inquiry was a difficult process to understand as it was not clearly laid out or structured. However, after considering publications discussing the methodology and examples of heuristic inquiry in practice, I realized that I needed to honour the phases of research as naturally evolving and intuitive processes. It was not until I had experienced the first few natural transitions between each phase of research that I understood this concept. The following sections outline my research process as it relates to the six phases of research described above.

**Initial engagement.** I came to my question when I approached my supervisor to brainstorm ideas about what I could study for my thesis. My interest in the brain injury area and the family of those with ABIs was clear as was my personal experience with the phenomenon itself. My supervisor asked me to contemplate my comfort level with using my personal experience and the family of those with ABIs as part of my thesis. My initial reaction was a positive one, thinking that it would not be an issue to use my personal experience and explore the experience of children whose parents had acquired a brain injury. After utilizing focus of inquiry, self-dialogue, and in-dwelling, I realized that this would force me to take a closer look at my experience after a very strong attempt to simply move past it and leave it in the past. I realized my supervisor was really asking me if I felt
comfortable looking at such a sensitive topic with a magnifying glass knowing the personal impact that it had on me.

Once this seed had been planted, I found it nearly impossible to turn away from the topic, reflecting the concept of focus of inquiry. Despite my initial hesitation, I started to explore the literature to determine if it was possible to explore the experience of children living with a parent with a brain injury. It was clear that this was a topic that had been ignored in the research literature. I also knew from personal experience that it was likely ignored in practice as well. Upon these discoveries, I worked to develop my research question by contemplating what was missing from the literature as well as what I wanted to know from others about this experience. I quickly realized that because there was little known about this phenomenon that a general question exploring the topic was necessary. Therefore, the following research question seemed appropriate for what I wanted to know: What is it like for adolescents and emergent adult children to grow up living with a parent with an acquired brain injury?

The next endeavour included outlining how I was going to explore this question using what I already knew: my tacit knowledge. Following heuristic inquiry research methodology, my design included conducting in-depth interviews with individuals in their adulthood whose parent acquired a brain injury while the participant was an adolescent. I chose to look at the retrospective account of this experience because I wanted to learn (a) how these individuals perceived their parent’s ABI, (b) how this event impacted their development into adulthood, (c) how they coped with the experience, and (d) what was beneficial and detrimental about the event in hindsight. I thought this
information would be the most helpful in meeting my aims of this research mentioned in Chapter 1. This planning stage started to overlap with the second phase of research.

**Immersion.** Immersion involved numerous periods of self-dialogue and in-dwelling to determine the key elements in my own experience to aid me in my literature review, recruitment, and in-depth interviews. I started this phase by planning how I was going to conduct this research by applying for ethical approval from the Conjoint Faculties Research Ethics Board (CFREB) at the University of Calgary. In this planning phase, I engaged in journaling to help myself reflect on my experience as well as what would have been helpful. Upon my initial reflection, I conducted a very brief literature search to inform my own experience while also addressing some of the concerns I had about my research design. In the process of outlining my research design, I engaged in a second self-dialogue process to help myself reflect on what type of design I would have responded to as an adolescent or emerging adult who had lived with my parent with an ABI. Upon this reflection, I completed and submitted the CFREB ethics application. Ethical approval was gained in July 2010, and then renewed with minor amendments in July 2011.

The second step in this phase of research was to conduct a larger, more in-depth literature review to determine what had been done, what elements needed to be considered for this research topic, what information or theories could inform the experience, and any gaps in current literature. While investigating the literature and reflecting on my personal knowledge of the phenomenon, I was able to solidify my interview questions to guide my interviews (see Appendix A). I used tacit knowledge, in-dwelling, self-dialogue, and intuition to guide my literature review.
The third step of this phase of the research was the recruitment of the participants. Recruiting participants required two rounds of recruitment efforts. In the first round which began in March 2011, I contacted the executive directors, service coordinators, and front line staff of brain injury agencies to determine their willingness to help me recruit participants. After gaining interest from three Calgary-based brain injury service providers (i.e., the Association for the Rehabilitation of the Brain Injured, Southern Alberta Brain Injury Society, and Brain Injury Rehabilitation Centre), I provided each organization with a standardized written call for participants that provided individuals with information about the study, participation criteria, participant roles, how to learn more about the study, and how to become a participant (see Appendix B for recruitment documents). This step involved using my tacit knowledge and intuition.

Each agency distributed the letter to their list of clients informing them of the study with a particular emphasis on the research being conducted by a student who is not affiliated with the organization. This was to ensure that interested parties felt safe communicating about their experiences which may or may not reflect the organization. This was also to ensure that individuals did not associate the services they received with their participation in the study.

In addition to a call for participants at various brain injury organizations, I also posted recruitment posters on bulletins throughout the University of Calgary campus (see Appendix B). Because of the hidden nature of this particular population, I wanted to ensure that individuals who did not access brain injury related services had the opportunity to participate as well. This method of recruitment was particularly effective because within one week of posting my first poster, I had recruited two participants. I
had also been contacted by one individual who chose not to participate in the study and
another individual who did not fit the participation criteria. Both participants had never
accessed brain injury services or any other formalized supports such as counselling or
support groups. Two more participants contacted me in response to the call for
participants circulated by agencies. These two participants were siblings and were both
very interested in participating and learning more about the experience of other
individuals who lived with their parent with an acquired brain injury. One parent had
contacted me to pass along the information from their children who had stated that they
wanted to participate. However, after several email exchanges, the two adult children
decided not to participate due to feeling unprepared to discuss their experiences.

The second round of recruitment occurred in July 2011 when all service provider
contacts were reminded of the study and informed that I was still recruiting. In this
process, I asked the service providers to circulate the call for participants a second time. I
posted more posters throughout the University of Calgary campus. I recognized that the
timing of this second round was not ideal as many individuals are less available in the
summer. However, in early August 2011, two more participants (siblings) contacted me
after their mother had informed them of the study. Both participants had moved outside
of the Calgary area but still wished to participate in the study. I decided that six
participants were sufficient for the purposes of this exploratory research.

The fourth step of my immersion process overlapped with the recruitment of the
participants. In this next step of immersion, I started conducting one to two hour, in-
dept interviews with each participant. Shortly after the initial contact, interviews were
scheduled with each participant. The consent form and a confirmation of the date, time,
and location of the interview was sent to each participant via email. Four of the interviews were conducted in person at the University of Calgary. These four participants read and signed the consent form indicating informed consent to participate in the interview (see consent form in Appendix C). One interview was conducted using Skype and another interview was conducted over the phone due to computer and technical difficulties. The participants that engaged in these long-distance interviews provided informed consent by reading the consent form, and stating that they agreed to the terms presented in the consent form on the audio-recording. All interviews were audio-recorded. Each interview began with collecting demographic information to provide the context of the individual’s story followed by the question and statement: Tell me about what it was like for you growing up living with a parent with an ABI. You might begin by focusing on what was it like for you before your parent incurred the ABI and then what it was like for you after your parent incurred the ABI (see Appendix A for details).

The interview loosely followed the interview guide as I used focusing, tacit knowledge, and my internal frame of reference to guide all six interviews. This is because the interview process as outlined by Moustakas (1990) emphasized that the interview is a natural conversation with a goal in mind. I created a basic interview guide because I knew it would help me stay on task while also giving me the freedom to explore topics that would come up. I also referred to my own experience in the interviews to help prompt the youth in sharing various elements of their experiences to enhance the richness of the data being collected. As a result, I was able to also develop a trusting relationship with each participant as they knew that I would understand the
complexity of their experiences. This helped me explore their story further than I had anticipated. Therefore, I frequently did not follow my guide in an effort to explore these unanticipated elements.

Each interview was transcribed verbatim. From each transcript, I created individual depictions. Individual depictions are narratives of my understanding of the participant’s experience. Each individual depiction was created based on the transcript to preserve the participant’s use of language and personal style of speaking. Upon completion of each individual depiction, the participant was given the opportunity to review and make corrections to his or her depiction over a two-week period. Each depiction was finalized upon the approval of the participant.

The fifth and final step of my immersion process was conducting the data analysis. I started to delve into developing themes and codes as I read each transcript and individual depiction. I used focusing, indwelling, intuition, and my internal frame of reference to develop each code and theme. Each code was assigned a different colour to underline the text reflecting that particular code. Once all of the transcripts were coded, themes were created based on the commonalities of each code. Upon the recommendation of several published works using heuristic inquiry (Djuraskovic, 2006), I created an analysis chart with three columns: Themes, main messages or issues, and content (see sample in Appendix D).

The column labelled “theme” was what I called the theme based on my grouping of codes. I placed all the text from the transcripts that related to each theme into the column labeled “content.” Content referred to the statements that the participants made in relation to that particular theme. Once I placed all the transcribed data into their
appropriate themes, I examined each theme and the content relating to that theme to develop the main messages column. The main messages or issues column refers to the meaning and essence of each theme. The development of the main messages concluded my immersion phase as I felt as though my mind was so focused on the data that I needed to step away from it to better understand the bigger picture.

**Incubation.** This phase of the research seemed to naturally evolve from the immersion phase of the research because I felt stuck and uncertain as to which direction to go in next. I quickly realized that it would likely be helpful to take a break from the data to help refresh my mind. As a result, I engaged in self-dialogue and in-dwelling to help refresh my mind and reflect on the data I had just collected. It was at this moment that I realized I had entered the incubation phase of my research. Although I attempted to step away from the data, I realized that my intuition and tacit knowledge continued to work as my thesis work would still come to mind when I was listening to the news, talking with friends, and reading seemingly unrelated materials. I realized that, as Moustakas (1990) and Sela-Smith (2002) explained, although I had consciously changed focus to work on other elements of my thesis work, my mind continued to think about the meaning of my data. Eventually, I surrendered to the “inner workings of the tacit dimension and intuition continue to clarify and extend understanding on levels outside of the immediate awareness” (Moustakas, 1990, p.29).

**Illumination.** My incubation period ended when I suddenly realized how I was going to categorize my data, present it in written form, and sequence the themes that needed to be discussed. Interestingly, this involved initially categorizing my data with a renewed focus and a single piece of paper for each theme posted on walls. I started
categorizing my themes based on the commonalities between each theme and their associated meaning. For example, I started to put themes together that related to the transitional experience itself while others might be better suited to the family experiences. I had revised my categories approximately three times before I became satisfied with the categories and their associated meanings. However, I remained open to their shifting and evolving as I began to describe my themes to others and went back to the literature to better inform my findings.

In this process, I condensed some themes and expanded others to better reflect the main messages being discussed as well as to honour each participants’ individual depiction. I gained a better understanding of the individual depictions, themes, and categories, enabling me to conceive of the group depiction: the common story and experiences of all the participants as well as my own experience.

**Explication.** Illumination naturally evolved into the explication phase as I needed to reflect on my own experience in addition to the participants’ experiences with this phenomenon. I considered how each theme first was reflected in my own experience to help me focus on the topic. Explication involved considerable indwelling, focusing on the internal frame of reference, and self-dialogue. With each new reflection, I was able to better understand and explain the events of my own experience. It became necessary for me to revisit painful and pleasant memories to become more aware of my thoughts, feelings, beliefs and judgments about my experience with the phenomenon. Because writing notes of my thoughts and feelings has always been helpful in my reflective process, I started to write down my thoughts as they occurred to me to aid in my
reflection. This helped me to remain focused and avoid self-inflicted distractions to avoid revisiting less pleasant events related to my experience.

Once I had completed my reflection, I felt I could also understand the experience of the participants in more depth. I closely examined the individual depictions to uncover new meaning and gain a more complete understanding of the experience of the phenomenon. This included revisiting the themes and categories to determine how well they honoured the unique experience of each participant. This process also forced me to revise my categories a fourth time until I felt that the themes reflected my own experience as well as that of the participants. This was how I was able to ensure that my final creative synthesis honours the richness of the data that the participants shared with me.

Creative Synthesis. This final stage of the research evolved from the explication phase as I felt able to write a narrative depicting the group experience of this phenomenon. I combined what I had learned from the literature, the participants, and my self-dialogues to share the results in a meaningful way. Because I have taken to storytelling, I thought a narrative sharing of the experience would be the most appropriate way to help other individuals the essence of the experience, as Moustakas (1990) described it. In this sense, my discussion in Chapter Five reflects the result of the integration of all my data. The goal of my creative synthesis was to have some element of this story resonate with the readers. I thought the most meaningful way to meet my goal of a creative synthesis was to write a short-story reflecting the experiences common to this phenomenon paired with the discussion of my findings.
Participant Demographics

A total of six participants were involved in this study. There were two men and four women. The ages of the participants at the time of the interview ranged from 18 to 32 years. When their parents had acquired a brain injury, the participants were 12 to 18 years of age. Two pairs of siblings also participated, and both pairs were male-female sibling pairs. In both cases, the male was the eldest sibling. One pair of siblings came from a blended family, where the stepfather acquired a brain injury. Another pair of siblings lost their father in the same car accident that injured their mother. All of the participants identified as Canadian. However, one participant also considered herself as Chinese, a second participant also identified as Lebanese, and a third participant identified as Greek. Two participants had a high school diploma. Three other participants had completed some college or university, and one participant had a college or university degree.

The causes of the parents’ injury were varied with two parents experiencing a trauma to the brain, one parent experiencing a traumatic injury and stroke, and one parent experiencing an illness-related injury. Two parents were male and two parents were female. Two parents were in a comatose state for two to eight months, with a hospital stay of four to twelve months. The severity of each parents’ injury was unclear, but it seemed that two of the four parents acquired severe brain injuries, while the other two parents acquired mild to moderate brain injuries.

Quality of Research

The quality of my research activities refers to the degree of rigour I used when conducting my research. As such, I will discuss three concepts to aid me in this
discussion including (a) credibility, (b) transferability, and (c) dependability and confirmability. Credibility refers to the extent to which my research is accurate, authentic, and a meaningful representation of the participants’ experience of the phenomenon (Vivar, 2007). Transferability refers to the generalizability of the data and conclusions to other contexts and circumstances (Vivar, 2007). Finally, dependability and confirmability refer to the clarity and transparency of my research protocol so that it may be replicated to yield similar results (Vivar, 2007). However, this last concept in heuristic inquiry is difficult because no one else could theoretically replicate my data because of my own personal experience and influence throughout all stages of the research protocol.

**Credibility**

Member-checking is an important part of the analysis in heuristic inquiry because it ensures that the researcher accurately understands the story told by the participants. Therefore, each individual depiction was reviewed by the participant over a two week period to make revisions, corrections, or comments to the document. Each participant had this opportunity prior to the analysis taking place. Only one participant responded with minor corrections on factual information, while the others indicated that they approved of the individual story. Furthermore, the participants had the opportunity to review the group depiction and themes developed to ensure that they agreed with the themes demonstrating the experience of living with a parent with an ABI. Again, the participants agreed with the findings, indicating that it accurately portrayed their experiences with slight variations. More importantly, the meaning of the group depiction was accurate for all the participants.
Transferability

The data collected for this study reflects the experiences of several individuals given a specific context: the timing of the experience in the participants’ lives, the unique interpretation of their experiences shared with me at a particular time, and the individual characteristics of the experience. Heuristic inquiry is aimed at using an insider’s experience to interpret the phenomenon as it is experienced by several individuals to identify commonalities and the shared meaning of the experience (Moustakas, 1990). Although my experience may be very different or very similar to those of the other participants, it allowed me to better understand what it was like to live with a parent with an ABI. Yet, because of my experience, it was also important to ensure that the participants came from different backgrounds, circumstances, and contexts than my own to ensure that my data was as transferable as possible. Because of my additional efforts to recruit individuals from diverse backgrounds, it is more likely that most commonalities and themes developed from the data are transferable to some extent to other adolescents and emerging adults who have lived with a parent with an ABI. There are some limitations, but these are discussed in Chapter 5.

Dependability and Confirmability

Engaging in dependable heuristic inquiry research suggests that I must be willing to acknowledge and represent experiences that are different from my own. My experience with the phenomenon was both similar and different from those of the participants. This allowed me to expand my understanding of the phenomenon to accommodate variable experiences and view the phenomenon more completely. Furthermore, because I had lived with a parent who acquired a brain injury during my
adolescence, I was likely to understand the phenomenon experienced by others in a unique way. My experience influenced how I interpreted the data, but my understanding of my experience was also influenced by the participants who shared their stories. Therefore, I would state that this research is dependable as I have been influenced by not only my own experiences, but also the experiences and stories shared by the participants making my interpretation of the data more complete and diverse than if I had simply considered my own experiences. Thus, my research is both dependable and confirmable as it honours the experiences of the participants in addition to my own.

**Summary**

In this chapter, I discussed the methodology I used to investigate the research question: What is it like for adolescents and emergent adult children to grow up living with a parent with an acquired brain injury? More specifically, I discussed my reasoning for choosing a qualitative methodology and my process of and justification for choosing heuristic inquiry to explore this research question. To provide you with a better understanding of heuristic inquiry, I compared and contrasted descriptive phenomenology to heuristic inquiry because Moustakas (1990) based his approach on descriptive phenomenology. I then discussed the core concepts used in heuristic inquiry to help you understand the assumptions of heuristic inquiry. Following this, I explained the phases involved in engaging in the process of heuristic inquiry and shared my specific process and procedure for collecting and analyzing the data. I followed this with a description of the demographics of my participants and a discussion of the quality of my data.
CHAPTER FOUR: RESULTS

I undertook this study to explore the research question: What is it like for adolescents and emerging adult children to grow up living with a parent with an ABI? Because participants shared their full stories with me to help me better understand their experiences living with a parent with an ABI, I believed that sharing the participant profiles was the most effective way of introducing both the participants as well as the results. Therefore, I will begin this chapter by describing the participant profiles containing their synopses of their stories. Then, I will share the results of the heuristic inquiry process in which 22 themes were developed and placed into one of four categories which describe adolescent’s and emerging adult’s experience of growing up living with a parent with an ABI. Each category will be briefly introduced followed by the description of the theme and supporting statements from in-depth interviews conducted with each participant. I will end the chapter with a summary.

Participant Profiles

I believe it is important for you to know the context of the participants’ experiences because the context can help you understand the complexity of this lived experience with real and concrete stories. By describing the participant stories here, I am introducing you to the participants as well as to the variability in the context of their experiences. Individual depictions of the participants’ experiences were developed based on the participants’ interview transcripts. A sample individual depiction can be found in Appendix E. The participant stories below are synopses or summaries of the individual depictions. The only exception to this is in my own story, which was adapted from a
written narrative rather than an interview transcript that resulted from my self-dialogue. For ease of reading, all of the synopses are shared in the first-person.

**Researcher Story**

I was 15 years old when my mother acquired her brain injury. I was in high school, and both my older brother and sister were in post-secondary schools. My mother is a single parent who was divorced from my father for over 15 years at the time of her injury. My father is Trinidadian, while my mother is Canadian. My father chose not to be involved in my family, and I had only met my father a total of three times at the time of my mother’s injury. Therefore, my siblings and I were not raised with the Trinidadian culture and we consider ourselves more Canadian than Trinidadian. Before the accident, my two older siblings and I were used to contributing to the overall functioning of the household out of necessity because it was difficult for my mother to run the household, care for three children, and meet our family’s financial needs.

My mom was 47 years old at the time of her injury. She was completing her PhD in Management and working full-time in a management position with a large marketing firm when she got into a car accident. When I learned of my mom’s car accident, it was like my world stopped in a moment. We were led to believe that it was a simple “bump on the head” and that she would be released from the hospital soon. As her symptoms like the inability to remember things from one moment to the next, difficulties communicating her needs and wants, increased emotionality and frustration, and ongoing feelings of confusion and disorientation continued to persist, the doctors insisted that she would be fine and that she be sent home. As her family, we attempted to support her as
best as possible, but I remember a distinct moment when I rushed to hug my mom, and it was like I was hugging a shell: I realized that the woman that I had just hugged was not the same woman I knew as my mother. She was so different in so many ways.

Six months later, my mom fell into a deep depression for several months before she came down with meningitis. She was in the hospital for a week as the illness cleared up. Upon her arrival home, we realized that her symptoms got worse. I continued to hold onto being a “normal teenager” until we sold our house because we could no longer afford to keep it. When my brother and I moved into a townhouse when I was 18 years old, my sister moved to eastern Canada, my brother and my mother’s relationship disintegrated, my mother decided to live on her own separate from her children, and my mother also started to make self-destructive choices, I realized that things were never going to be normal again. My world had been blown apart by a “bump on the head.”

I began to gain more hope as my mother started to put her life back together with the limited support I could offer and no formal supports. When the dust finally started to settle, I could look at the damages caused and started to repair my own life. Eventually, my mother was officially diagnosed using improved brain imaging techniques to reveal evidence of passed brain trauma. Perhaps too little too late, but it was validating enough for my mother and those of us who stood by her. My mom’s brain injury changed us all. It changed everything. Now that I am 27 years old and looking back on my experiences, I know I grew from the experience and learned to appreciate my daily life while always looking on the bright side of things. I am now a full-time graduate student who continues to look for answers and provide answers to other people like me.
Jessica

When I was about 12 or maybe 13 years old, my father started getting headaches. I was about 14 years old when he went in for surgery. I was in school and I think I was pretty shy. My brother is two years younger than me, and I was always pretty close to him. I come from a Chinese-Canadian (1st generation) family, and my parents have always been kind of secretive, especially about health problems. I guess that was their way of protecting me and my brother from bad things. We could have asked, I guess. As the children of parents who never tell you anything, you get used to accepting what they say and never asking for more information. I wasn’t really close to either of my parents because they didn’t really share much with me, but I was always close to my younger brother. We were always in things together.

I knew my dad was starting to get really sick, but my parents didn’t tell me that he had cancer or that he was booked for surgery. He had developed a brain tumour, which had to be removed as soon as possible. The surgery could have killed him and we didn’t have any time to prepare for that. The doctors didn’t really tell me and my brother what could happen after the tumour was removed. I think the doctor’s told my mom what had happened and what to expect, but she never told us. Because I didn’t know anything, I kept thinking that the changes after the tumour was removed were because he was depressed over his illness and surgery.

After the surgery, he would have a really hard time remembering our names, and I feel like his personality is completely different now. He has so much trouble with his memory that it’s really affecting his work in a middle management position. His job
performance apparently declined after the removal of the tumour, which didn’t go over
very well. It was like night and day, how different he was. It’s like I lost him even
though he is still around every day. Some days, I think I’m catching a glimpse of who he
was, but I think I’m imagining it sometimes.

I just hope for him to revert back to who he was. I’m still grieving for my dad as
I knew him. I don’t think he’ll ever be the same. It’s just he doesn’t find the same things
funny, and he sometimes gets emotional, when before he was never emotional. At the
same time, he’s emotionally closed off because he doesn’t want to tell anyone about it.
Sometimes he’s really emotionally open, too. It’s just not like him to be on either
extreme for his emotions. Also, my dad has completely lost his sense of humour. I
didn’t know someone could lose something like that. He used to be really goofy and
embarrass me all the time. I kind of miss that now.

I’m 21 years old now and I think I have adjusted. I really feel like I developed a
lot of parts of myself, and now I can be really independent. I realize that it’s past us and
we will just make the best of what’s happened, even though he’s different now. I think
it’s getting better. And that’s helping me feel better. I feel like I’m a lot stronger. I
developed a lot of skills and I met a lot of people, and I grew more self-confident. I
became less shy also because life can be too short. I would never say it was worth it for
my dad to get sick or anything. I really wish that my dad didn’t get sick. But I mean it’s
been good for my overall development.
Tammy

Before the accident, I had an awesome upbringing. A lot of my friends always used to tell me that they were jealous because my parents were so happy, they talked often, and they never really fought. My mom and I didn’t have the best relationship in the world before the accident. I just had a better relationship with my dad. I was my dad’s little girl. 100%. He knew absolutely everything about me and my life. My older brother (Jason) and I would have our good days and our bad days.

I was 17 years old and in my senior year of high school when my mom had her brain injury. My Mom, Dad, Aunt, and Grandpa all got into a car accident December 26th. The car had rolled and then had been hit by a southbound vehicle. My mom was 42 years old and she was driving at the time. I think she suffered the most from the accident. My aunt pretty much just walked away from it. But my dad and granddad had passed away. We didn’t know what state my mom was in. We didn’t even know if she was alive. We didn’t know because every time a doctor would come to talk to give someone an update, he would pull my aunt or grandma out of the room, and then my aunt would come back in and tell us what they just told her.

My brother and I stayed at the hospital for the first week. They didn’t know she was going to make it out of the coma alive, and they basically told us that if she does make it out of the coma, she could be a complete vegetable. I was grieving for my dad, and worried that my mom was going to die. We had to move in with my aunt and my grandma because we couldn’t stay in an empty house. Then, I had to go back to school in January and my mom was still in a coma. People would come up and say, “oh I’m so
sorry!” and all I wanted to do was to go about my day like a normal kid. I guess I just needed that routine back in my life to try and get my mind off of only the accident and only my mom. Once I got back into the swing of things at school, and people started going back to normal, it was great.

When everything stabilized in the hospital, she was up in the trauma unit which is where she came out of her coma six months after the accident. The first time she opened her eyes, she spoke me and my brother’s names, wondering where we were. She started going to a physiotherapy class within the hospital to get her arm movements and stuff back and she was in the hospital for two more months before she went up to Ponoka for the rehabilitation program. She was there for two years. My brother and I were still living with my aunt at that time, but I moved out when my mom went up to Ponoka. At the end of the day, it wasn’t my home.

When she would come to visit us, it was hard because it was like having a new baby at home, where you had to reteach things to. The memory loss is the hardest thing. It’s the small things, like remembering Christmas and stuff like that. Her personality completely changed. She was like a new person. She would have her good days and her bad days. It was difficult, but we knew that it was what we were signing up for when it all happened. My mom survived, and I didn’t want to take for granted that I had her back. I’ve never been closer with my mom in my entire life. After the accident, my brother and I helped each other out a lot. He’s changed so much since the accident. He went from being a rebellious child to saying things like, “hey mommy, how are you?” He’s improved the most.
Now, I’m a lot more of a forgiving person. I’m 21 years old, but I’m a different person than who I used to be. Everything I do, I always say to myself “is this the best thing I could be doing?” Is this something that would make my dad proud? Is this something my mom would take for granted? I definitely say I’ve changed in a positive way. I still have my bad days where I just kind of breakdown. My mom reminds me that I’m human, and this is normal. I am a lot more responsible, I think, because I had to grow up really quickly. I had to go from being a teenager and having fun to being an adult and dealing with these problems.

Now, I guess I kind of have my own little family. I would say that I have somewhat of a normal life again. I guess it kind of feels like pieces are finally starting to fall back into place. They are starting to go back to where they used to be. It’s just never going to be the same as it was, but it’s gone back to normal. Like a new normal now.

Jason

Before the accident happened, we were like any other family. We are a Lebanese-Canadian family, so family was always important. Before the accident, when my sister (Tammy above) and I were younger, it was obviously good. But then we hit high school, and we’d hang out with different people and different kinds of groups. I was her “big brother” in high school and took care of her where I could. My relationship with my dad was a lot better than with my mom because it was a father-son kind of thing. But when I got in trouble, my mom would deal with me. My relationship with my mom was good. She would guide me, and tell me what to do. If it was bad trouble, she would tell me what to do.
I had just turned 18 years old, just graduated high school, and was working full-time. I was out a lot with my friends, going to the bars, and getting into some trouble here and there. Then it happened. My mom, dad, aunt, and grandfather got into a car accident the day after Christmas. My dad and granddad didn’t survive the accident, while my aunt walked away to call for help. My mom survived, but was severely injured. Mom was 42 years old when she got into the car accident. She was in a coma for like eight months. I was so happy that my aunt was at least ok. I think it kind of gave me a bit of hope that my mom could walk away. I think her surviving helped a lot.

It all hit me at once when I found out my dad passed away. But then, my mom was in a coma, so I almost didn’t put all my attention into grieving for my dad. My sister and I realized that our dad passed away and that was still hard, but the fact that my mom didn’t know was kind of the worst part. The hardest part of the experience was thinking that my mom wouldn’t wake up. I think not knowing what was going to happen was really hard because I couldn’t do anything. It just kept going, wondering day to day if maybe she would wake up that day.

On top of everything, I was 18 so everything in my dad’s estate went to me, and I really didn’t know what I had to do with it all. I had to deal with what will we do with my dad, and what will we do with the legal stuff and the house and all the bills that weren’t paid. With my grandma and my aunt, they were the main people that helped my sister and me. They called around and told the insurance companies and banks what happened. At the time, all I wanted to do was just stay at the hospital. But I had to deal with all this stuff.
I went back to work in March because I was dealing with some money problems. I had some problems at work though because I would start thinking about my mom and what we don’t know and that would all come up, so then I couldn’t work. I couldn’t pretend like everything was normal, and I couldn’t stop thinking about what was happening. It was really hard balancing everything going on in my life. Life doesn’t stop when you deal with this kind of stuff. You have to keep working; you have to be there for your family; you have to keep your friends; you have to keep going. So I was busy a lot. All I wanted were things to slow down. Being the oldest left me with no one to turn to for guidance. I had my sister but we were both lost. It would have been nice having someone there that has been through the same thing who I wasn’t related to. They could guide you through everything so we weren’t so alone.

After my mom woke up, things started to get better. She was making progress, even if it was slow, we still had her. I think what changed is that now I had hope. I was happy again. I started doing the same things, getting excited over the same things, and actually participate in life again. My mom was still at the hospital for two months after she woke up. I got excited to see what kind of progress she’d made each day. She was different when she woke up though. She’s much more relaxed about rules. She also asked a lot of different questions like how we coped at the beginning. I think it hurt her that she missed two years of our lives almost. She was in Ponoka for a rehabilitation program for two years after she was released from the hospital. It has been harder to understand my mom now than before.
My sister and I get along a lot better now. We are really there for each other. Basically, we grew up, and we matured. She became my big sister too. It was easier to go through that with my sister than with my friends. That’s what made us a lot closer after the accident. I’m 22 years old now, and I think I have accepted the fact that my dad passed away and that my mom will always be different. I’ve changed so much because of this. I don’t want to disappoint anybody, let alone my family. Looking back on things now, I realized I had to mature so quickly. I had so many more responsibilities in such a little amount of time. It was really hard at the time, but it helped me out a lot. I’m not going to say it was a good experience, but I learned a lot from it. I would think: if I were doing something bad, what would my dad think? I think it’s got a lot to do with it – he keeps me in line still. I realized what’s more important in life. I think I have a different perspective now about my life, and that life is too short to worry about the things that could happen in the future or being mad at people. I could die tomorrow, and so I’d better make the best of today. I think recognizing the hopes my parents have for me really is what made me change. I always want to fulfill their dreams for me. The family is really close now. It’s a big family, but we are really close. I don’t miss family parties anymore because there really isn’t anywhere else I’d rather be.

Penny

Before the accident, my mom was always really sharp witted and you couldn’t get anything past her. She was always so vibrant, she still is, but not to the same degree. Our family is essentially a Greek-Canadian family. I have two younger sisters, and I would say we were as close as three teenaged girls could be. My relationship with my
mom had always been a bit rocky. I love my mom but we would fight a lot. I always wanted to be a lot closer with my mom. My dad and I were always pretty close too.

It was two days after my 16th birthday. I was in high school in a small community just outside of Calgary, and my mom worked as a bus driver and sometimes as helping out in the library at school. My mom was 41 years old at the time of her accident. She was on one of the buses that had an overhead rack for bags and stuff. She smacked the back of her head, and it stretched a muscle in her neck and head, and then it went back into place. She went to the hospital because she was feeling sick all day, but then she was released. We weren’t told anything about brain injury. She was really dizzy and spacey. We didn’t know what was going on, and she was going to doctor after doctor after doctor. After a while, they diagnosed her with this injury, which they explained was a unique kind of brain injury. She was nauseated and dizzy for a very long time. She would even black out sometimes. This all happened two weeks after a girl in my school died in a bus accident.

There were days that my mom couldn’t remember what had happened. I remember a day when my sister was really upset about the girl’s death, and my mom asked why she was so upset. I had to explain to my mom that she was really upset that the girl died. It was really hard having to re-explain everything to her one or two times a week. She gets completely disoriented a lot too. My mom also deals with a bit of claustrophobia which is new since her accident. She had a lot of problems keeping things organized because she had problems thinking clearly a lot. It was really inconsistent, though. Some days her memory would be fine.
I always wanted to help my mom where I could to make her life a bit easier. But, I felt so bad sometimes, and like I was a lazy daughter. Feeling lazy was a big thing for me too. I couldn’t help out as much as I wanted to, and sometimes felt burdensome to my mom. I tried so hard, and I remember getting so mad at my mom because I didn’t understand that she wasn’t forgetting on purpose. When I’m not able to help her, I feel terrible. When I am able to help her and I don’t, I feel terrible. When I do help her, I feel like I’m not doing it enough. I tried to help my family out as much as I could.

Since all of this happened, I can’t not be there for someone. I have to go out of my way to help others, it’s weird. In a way, it helped me cope with things to focus on other people rather than myself. It was easier to help other people than it was to only think of myself, especially when so many other people needed help. My family means a lot to me. So I want to make sure that they are ok. I am very protective of them. If something goes on with my sisters, I get crazy protective of them. Think of it as a momma cougar if you will? It’s one thing for us within the immediate family to say something, but if someone outside of us says something, don’t you dare.

I don’t really know how or even if I did cope with what happened with my mom. I guess I did whatever I had to do in the situation, but the same year was packed full of other crap. I started to feel inadequate in a lot of ways because I couldn’t help my mom, I couldn’t keep friends, and I couldn’t keep a boyfriend. So when I started thinking of one thing that started to really bother me, I had to switch to thinking about something else. I threw myself into school, academics, and creative projects. I think these helped me to deal with things indirectly. I was able to get most of the bad things out of my life,
even if it was all at once. I managed to do it and I’m better for it now. I’m able to just say to myself that these things are what really matter in my life: my mom and my family.

I’m 18 years old, and I’ve started looking out for myself a bit more. As soon as I started worrying about just my family and friends, everything started getting better. I think I can better cope with a lot of different things at once because that’s what I had to do. So now I have those skills for the future. I started to get more relaxed about some things too because I recognized my priorities. So I wouldn’t stress out about the small stuff. I see myself as stronger person. As for my family, I think we are better at managing our problems as a family. I think having this brain injury in our family has made us work together better than we did before. It has changed my family and we are a stronger family. It’s not like I would say that the brain injury was a good thing, but I was happy with the change in my family, in all of us really.

Rebecca

My stepfather came into our lives two years before his brain injury. He was kind of like Knight in Shining Armour that came into our lives. My mom was a single mom for years. My mom raised me and my two older brothers by herself for seven or eight years before my stepdad came into the picture. The responsibility of life was shared with someone else now. My oldest brother (Tyson) was a huge brat about my stepdad coming into our lives. He thought it was the worst thing that ever happened. My mom and brother fought a lot during that time. They still do. It’s just their dynamic. We were a fun family, and we were a team. We were a pretty tight knit family.
I was 11 or 12 years old when my stepdad was injured. He was about 39 years old at the time, and he was drunk and horsing around in the summer before school started. He got on the hood of his big Ford truck while a young kid who was working for him was driving, and he fell off. The car wasn’t moving very fast, but it was still a significant fall. When he fell off the car, he instantly passed out. He was taken to the hospital right away where he went into a coma for about a month. In the meantime, he had about seven strokes while unconscious.

It was really hard at the time because I was too young to stay at home. My brothers stayed at home, and I was kind of bouncing from a friend’s house to another friend’s house trying to find a good fit for me. Because when that was all happening, you know, I was just pre-pubescent, and I was also pretty lost. It was really an emotional time for me and I was confused a lot. My mom went and lived in Calgary so she could be there every day because you can’t just leave someone at a hospital and put them under the care of the nurses. There is way more care than just what the nurses can do for someone.

My brothers were at the house having house parties every weekend. They were like out of control teenagers. And I wasn’t with my family anymore at that time, because I needed a parent there, and I didn’t want to stay just with my brothers. Everything changed after the brain injury. It was really hard on my mom, I think, because in a moment, her dreams were gone too. I would get upset when my stepdad would be angry at my mom. She was his main caretaker, so she would get it first. Their dynamic is
definitely not like that anymore, but it was for a couple years. He came home about five or six months after his accident.

When my stepdad came home, I had to grow up really quickly because there were just a lot more responsibilities. I had to do a lot of things that kids my age weren’t responsible for doing. We all needed to work together to make things good. The first couple of years were really tough just because he had a lot of emotional outbursts, that he didn’t know how to control. He was very child-like at first. The doctors also didn’t know at this point, what medications he should be on and at what level. It was changing every day.

When I started the school year, everyone at school looked at me different and treated me different. People at school knew what had happened. Living in a small community, with a small class, it’s hard not to know what happened. I hadn’t seen a couple of my really close friends for a while. It was tough trying to explain to them what happened and making them understand the severity of what happened. I lost a lot of friends that year too.

Eventually, my frustration and anger turned into acceptance and understanding. I realized that this is my family and this is who we are and this is what we do. I guess I came to terms with it. It’s just my life. I also joined air cadets which helped a lot too. My family also became really involved with the church right after that happened. The church people were very supportive right when that happened, too. It was just being part of something that was fun and my whole family was involved with it.
My relationship with my dad now isn’t super close, not in the sense that I am with my mom. I talk with my mom every day. I don’t think I’m as close with anyone as I am to my mother. My relationship with my brothers was always good, and I’ve always been able to go to either of them if I had any issues. We are still a really tight knit family. Even though we all live somewhere else right now, we all keep in contact by email and Facebook and the phone.

Now, I’m 28 years old and I really think this whole experience has shaped me. I learned to look on the bright side of life. I guess it just made me realize how precious life is, and how you can’t take life for granted and you can’t take the relationships and the people you love for granted because in an instant, something crazy can happen, and they might not be there. I think it’s really made me a compassionate person for people who are in odd situations. I give a lot of love and I care a lot about strangers that I just walked down the street past. I’m also really good at communicating with people when I feel like they’ve stepped over boundaries or if they’ve hurt me in any kind of way. Learning responsibility at a really young age has made me very independent. I’ve never had to depend on anyone else for anything. Now, at 28 years old, life’s really good.

Tyson

My relationship with my mother was odd. My mom comes from an Irish-Canadian family, but I would consider us pretty much Canadian. Because I was the oldest child and my mother worked a lot of hours when I was a teenager, I was deferred to as a second parent in a way. So of course, when my stepdad came along, I was relieved of my duties and I could go back to being her teenaged son. Then he was
unwell, and things went right back to the way they used to be. My stepdad was a functioning alcoholic. My mom and stepdad were only together for a few years before this accident. Overall, he was quite good to all of us. I’m not really close with my stepfather, but his injury definitely impacted my family as a whole. My brother and I have an interesting dynamic and we got along really well. We were both social people with jobs and friends. We got involved in the rave scene, which is still in both my and my brother’s lives. The raves were great because I could go out with my siblings, dance all night mostly without drugs, and bond. My sister (Rebecca) and I, we’ve always had a good understanding. She’s almost 4 years younger than me, and there is lots of love. She was kind of away while my stepdad was in the hospital. She was at my family friend’s house because she was like 13 or 14.

I was 16 years old at the time of my stepfather’s brain injury. My stepdad normally drove, but we stopped at the liquor store on our way out of town. So he sat in the back, while my dad’s employee drove us back. My stepdad was wasted. Then we get home, and we had this big Ford truck going 30 Km/hour at best. So my stepdad decides it would be fun to climb through the truck into the back. It became really annoying for me, because he’s being stupid. Then he’s on the roof of the topper to eventually sit on the top of the roof of the cab. Then, my stepdad slid down the windshield, and sat on the hood while we’re driving. We were going literally 5 Km an hour with this drunk asshole on the hood of our vehicle and he points one way and falls right onto the concrete. My mom goes off to the hospital and I take my brother and sister home.
My stepdad wound up spending either three or four weeks in a coma and then having experienced eight or nine strokes during that time. The morning after his accident he was rushed by STARS ambulance to Calgary. My mother ended up spending the next several months in Calgary living at the hospital. My sister went to live with a family friend and she was there for the fall, up to Christmas, and maybe just after. My brother and I stayed alone at home while my mom was in Calgary nursing my stepdad for six months. I really enjoyed the freedom.

My stepfather came home around six months after his accident. I think it was way too early. He really went after me. At first, for the first month, he cried all the time because his medication was making him so emotional. Then, when he started to get more ambulatory, he was trying to discipline me like he was my father. He wasn’t actually in that role before, and at 16, I was very independent. I got used to being the parent in a way while both of mine were in Calgary. I had done this before when my mom was single, so I just had to do it again. I was also dealing with my sexuality and coming out in the 90’s which was different than coming out now. But, he would pick me out, and then try to discipline me.

When I went back to school in Grade 12, I really got into things and I really got into my classes. I got involved in theater and all sorts of stuff. My life kept going, and I kept dealing with things as they came, but every now and then, I’d hit something that was too much. It was challenging to keep my job and keep the house and go to school and keep my commitments - be connected to my mom and stepdad in Calgary. It was very busy. That’s also when I started going to this church. These new church people were
very fundamentalist and not really with it kind of folks in some way. They started helping our family and this church community is helping my mother and they’re paying for things and it’s nice. It fulfilled an emotional need that was obviously missing. It’s good to have caring people there helping. I even took my pride necklace off and put a cross on. I should have known that something wasn’t right about this church, and I didn’t like what was happening to me. I left the church by July after my stepdad’s accident. They got my family at an emotional point. All in all, it was good because they offered fellowship when I didn’t have much else. I guess my life with my stepdad’s injury became the new normal. Just with my mother having to take care of one extra person.

Now, I’m 32 years old, and I am with my common-law husband. Many of my experiences and perspectives came from my stepdad’s accident. I think some of the hard lessons I learned about taking care of myself, being able to see the good despite the harsh days. I was able to thoroughly and legitimately enjoy some of the things that I did during that time period after his accident. I really enjoyed High School, and it was a good outlet for me. I think that I’m pretty optimistic. I’m pretty hard working. I’m loving, and I think that these experiences made me stronger. It gave me some of the emotional tools. I’ve always felt like I’m a bit further ahead than some people my age. I feel like what I learned from my stepfather in de-escalating him helped me de-escalate cops and use those skills in my work. I’m actually considering one of my professional steps is to take counselling courses at the University of Manitoba. I’m quite happy with my life now. I mean, it’s cliché to say something like this, but, that’s what happened and this is who I
am. Would it be better if my stepdad didn’t have a brain injury? Maybe. Maybe not. It’s kind of Buddhist in a way. It’s like, it is what it is.

**Categories and Themes Characterizing the Experience**

Based on all seven stories, 22 themes were created to describe the retrospective experience of adolescents living with a parent with an ABI. Each theme was sorted into four key categories that characterize this unique experience: (a) parental ABI impacts adolescents and emerging adults, (b) parental ABI changes the family system, (c) parental ABI and external supportive resources, and (d) personal coping with parental ABI. A summary of these four categories can be found in Table 1. Each of these categories and themes is discussed in the following sections.

**Parental ABI Impacts Adolescents and Emerging Adults**

The acquisition of a brain injury by a parent has a life-changing impact at the time it occurs and on an ongoing basis. In describing their experiences of growing up with a parent with an ABI, the participants described the impact of the experience on them from the moment they first learned of the injury to the moment they accepted the injury as a new way of life to the time of the interview. This category is structured to provide an understanding of the impact of an ABI on these adolescents and emerging adults from the moment they learn of the injury to the moment they accept the injury as a new way of life. The themes included in this category are (a) ABI as a life-changing event, (b) feeling busy with depleted resources, (c) the sudden increase in responsibility leading to a sense of maturity, (d) the uncertainty of the future, (e) feeling unheard and disregarded, (f) complex and conflicting emotional experiences, (g) grieving for losses and changes,
Table 1

**Summary of Categories and Themes**

<table>
<thead>
<tr>
<th>Parental ABI Impacts Adolescents and Emerging Adults</th>
<th>Parental ABI Changes the Family System</th>
<th>Parental ABI and External Supportive Resources</th>
<th>Personal Coping with Parental ABI</th>
</tr>
</thead>
<tbody>
<tr>
<td>• ABI as a life-changing event</td>
<td>• The view of the non-injured parent</td>
<td>• Informal supports</td>
<td>• Tackling the problems</td>
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<tr>
<td>• Feeling busy with depleted resources</td>
<td>• The view of a parent with the ABI and the resulting changes</td>
<td>• Helpful informal supports</td>
<td>• Tackling the emotions</td>
</tr>
<tr>
<td>• Sudden increase in responsibility leading to a sense of maturity</td>
<td>• Changes in family relationships</td>
<td>• Unhelpful informal supports</td>
<td>• Avoidance and distraction</td>
</tr>
<tr>
<td>• The uncertainty of the future</td>
<td>• Changes in family roles and responsibilities</td>
<td>• Formal supports</td>
<td>• Compartmentalizing stressors</td>
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<tr>
<td>• Feeling unheard and disregarded</td>
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<td>• Helpful formal supports</td>
<td>• Maintaining a sense of normalcy</td>
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<tr>
<td>• Complex and conflicting emotional experiences</td>
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<td>• Unhelpful formal supports</td>
<td>• Optimism and hope</td>
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<td>• Grieving for losses and changes</td>
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<td>• The need for formal supports</td>
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<td>• Signs of accepting the parental ABI</td>
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<td>• Personal growth and development after the parental ABI</td>
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(h) signs of accepting the parental ABI, and (i) personal growth and development after the parental ABI. I will describe each theme in the above order in the following sections.

**ABI as a life-changing event.** Overwhelmingly, a parental ABI was viewed as an event that changed everything in the adolescent’s life. Everything that they knew was no longer a part of their lives. As Rebecca explained:

> Everything changed. You know, like our routines changed, things we could do changed, planning changed, everything. Emotions towards each other changed. Because all five of us had a completely different experiences. But it was all very taxing and hard and challenging for everyone (line346).

The parent’s ABI acted as a catalyst for a series of changes that occurred as the adolescents grew accustomed to their “new normal.” Similarly, at the time of learning of their parents’ injury, the participants reported feeling the shock of a sudden event that was described as hard, difficult, or challenging. As Jason explained,

> Just getting through it was hard. Like just from the littlest thing to the biggest things is what made it hard. And you can’t really like name anything specific, and everyone is probably different, but I think like the smallest things… But they all hit at like once. Once you get through those really hard things, it started to get easier. But at that certain time, it was really hard (line 650).

Initially, the participants viewed the ABI as an event that was clouded with uncertainty. Tammy best described this sense of shock and uncertainty coupled with the need for clarity in the following statement:

> We went up there (to the hospital) and my aunt had to go identify my mom because she didn’t have any ID. And it was probably about six hours before we
found out what happened with my dad. And the whole time, me and my brother were saying, you know, “where’s my dad, where’s my dad, where’s my dad, where’s my dad?” and they couldn’t tell us. They didn’t know (line 147).

It seemed that most participants viewed their parent’s injury as a difficult experience because of the suddenness and uncertainty of changes that occurred at the beginning of the experience.

Although the participants knew their lives had changed, they were unaware of the full extent of these changes. Participants made several references to putting the pieces back together, having their life come together, having life going back to normal, or in my own story, having the world stop only to start again as something new. Tammy stated:

I guess it kind of feels like pieces are finally starting to fall back into place.

Finally starting to go back to where they used to be and, you know. It’s just never going to be the same as it was, but it’s, you know, kind of gone back to normal (line 851).

In making references to regaining a sense of a new, normal life, the participants appreciated being able to start again and embrace their new life.

In addition, the participants came to realize the finality and the permanence of their parent’s injury. In other words, their parents acquiring a brain injury was something that had changed their lives forever. Penny described the shock of the long-lasting nature of the injury:

It’s something that it’s going to be with you forever, and it’s something that is going to stay with you forever. As much as you don’t think that it’s going to affect you as much as you think it will, like it most definitely does… It’ll just be a
little fence that you are always going to be beside, you know? You won’t get over it, and it won’t be gone forever, you know (line 1006).

By acknowledging the permanence of their changed life, the participants were able to begin to accept their new normal. All the while, adolescents need to continue to be adolescents.

Some participants described other events that can be typical of the self-discovery process that characterizes adolescence as life-changing. Tammy and Jason both lost their father in the same car accident that severely injured their mother. Penny was also grieving for the death of a classmate that occurred two weeks prior to her mother’s injury. Tyson was in the process of acknowledging his sexual orientation, while Rebecca was just beginning her adolescent transition at the time of their stepfather’s injury. Jessica was managing the uncertainty of her father’s cancer. Despite the feeling of life stopping for a moment, there was also the sense of life continuing at a natural, normal pace with this massive life event that had changed everything that they knew.

**Feeling busy with depleted resources.** With this life-changing event, the adolescents were expected to take on more responsibility. Many participants described feeling as though they did not have as much time to effectively deal with what had happened to their parent. Interestingly, the participants who reported feeling exceptionally busy with few resources (i.e., emotional, financial, physical energy) were the eldest children. Tyson explained that he struggled to maintain all of his commitments while also managing his home life: “It was challenging to keep my job and keep the house and go to school and keep my commitments and be connected to my mom and (stepdad) in Calgary. It was very busy” (line 422). Jason described a similar challenge:
Like, busy a lot. And hard, you get frustrated. You get angry, impatient, anything like that. Plus, we always had to meet with the doctor so that they could talk to us about mom, and that would take time out of your day. And then, it’s just everything. We’re not getting enough sleep. Everything like that, while still paying for everything to get up there (the hospital) and back and still like, moving to a new house (line 227).

Jason later described the need for self-care and the lack of time to effectively do self-care activities because of competing demands:

You just kind of want to take a breather, and work on your own time. But you gotta work on everybody else’s. So, that was just basically the hardest thing…

Dealing with that (finances, accident, grief, caretaking for sibling, etc.), friends that wanted to see you, family that wanted to see you, just everything. It was just busy all the time... I don’t want anything to be in my schedule, I just want to sit down and relax. And just, kind of hang out, I guess (line 233).

The lack of time to take care of oneself was problematic. The participants, including myself, reported feeling tired, drained, and stressed.

Money as a resource became a concern at the initial time of the injury. This is primarily because one of the income-earners for the family was now unable to work. As a result, the eldest children were then expected or expected themselves to find employment to compensate for the loss of income. This financial strain contributed to the sense of feeling busy and having few resources. Employment was typically coupled with full-time school, extra-curricular activities, visiting their parent in the hospital or
caregiving, and helping to run the household. Jason described the necessity of having a job because of the numerous expenses of his mother’s injury.

You always gotta have money, you gotta have a job and money to afford things. So when you don’t work and you gotta go to the hospital every day and get through it, and go see and do so many things, money is a big play in it. Like they always say it doesn’t matter… You can always make more money, but not at that time (line 647).

As an unfortunate reality, strain on all of the resources became one more stressor for these adolescents to manage at the early stages of this life event.

**Sudden increase in responsibility leading to a sense of maturity.** Participants described feeling the need to help both the family and their parents more resulting in increased responsibility. As such, all the participants reported feeling more mature or older than their chronological age resulting from the sudden increase in responsibility. This increase in responsibility included a variety of activities ranging from more household chores to caregiving for siblings or their parent.

I actually started working before I turned 14… I was working and I was helping contribute financially to the household. I didn’t just have the one chore a week anymore. It was making sure everything (that) needed to be done (was done). Grocery shopping, going to the PO Box to pick up our mail. I had to do a lot of things that kids my age weren’t responsible for doing (Rebecca, line 567).

In taking on this additional responsibility, most participants expressed feeling grateful for being there for their family and helping out where they could. Although participants appreciated being given the opportunity to take on the responsibility, many mentioned
feeling unprepared to accept the magnitude of what needed to be done. Therefore, there was an overwhelming sense of needing to mature quickly.

You had to mature so quickly. Like you had to mature so quick and you had so many more responsibilities in such a little amount of time. So it was really hard at the time, but it helps out a lot. Like a lot of my friends are just maturing now.

But I did it when I was 18, because I had to. But that was really hard at the time (Jason, line 643).

Similarly, Tammy explains her conscious choice to become an adult immediately in the following quote:

The day of my graduation… When I looked up and my mom and her nurse were sitting up there and the hospital let my mom go to my graduation, and I looked up and said, “My dad’s not there”. And it broke my heart, but I said you know, I’m done high school. I’m not, not a high school kid any more. I need to grow up. And I need to grow up now. Because I have to take care of my mom and I have to make my dad proud. And that was it. From that day forward, ‘cause I’m not a kid. I’m an adult. So act like one (line 785).

In making this choice and taking on this sudden responsibility, there was a sense of missing out on other activities because they had to mature quickly. Although Tammy did not state this directly in the following quote, her reaction to her statement (i.e., tears exemplifying sadness) revealed her sentiments:

It was hard because a lot of my friends were still young and they still wanted to go out and do all this stuff. It was like, you know, I don’t. I would rather sit at home
and go watch movies with my mom and eat popcorn than go out to the bar with you guys (line 792).

Some participants openly mourned the loss of the adolescent life that their friends enjoyed, while others stated feeling indifferent to the loss because caregiving or supporting their parent’s recovery was the least they could do for their parent who had raised them.

Furthermore, the participants all revealed feeling conflicting emotions regarding their experience. While participants indicated that they felt happy about taking on this responsibility, many also indicated feelings of sadness and potentially resentment towards their parent(s) because of this overwhelming increase in responsibility. Tyson explained:

It’s cliché to say something like this but that’s what happened and this is who I am. I mean, would it be better if (stepdad) didn’t have a brain injury? Maybe. I just have no idea where or how that would have affected my life… Upon reflection, the biggest thing, I guess it goes back to what would have been better this way or better that way. I think my mother could have been a bit tighter with some things (line 739).

These conflicting emotions were subtly expressed by the participants regarding all elements of their experience as it seems that this conflict continues into adulthood as they searched for meaning and ways to understand their experiences.

The uncertainty of the future. Most of the participants described some uncertainty at the beginning of this life event. This seemed to be the “limbo” of the transition. This uncertainty related to the adolescent’s, the parent’s, and the family’s
future. Many participants reported feeling uncertain due to what they did not know about their parent’s injury and the impact it would have on their family. Rebecca described her living situation immediately after her stepfather’s injury:

I was too young to stay at home [while stepdad was in the hospital]. I was kind of bouncing from a friend’s house to another friend’s house trying to get a good fit for me. I was just pre-pubescent and I was also pretty lost (line 189).

This feeling of being lost was common amongst the participants, especially those who were not included in communication about their parent.

This sense of uncertainty seemed to be triggered by a lack of knowledge or understanding. Plainly put, it was triggered by what the participants did not know about their parent’s condition. Penny described a sense of helplessness as she and her family continued to search for answers about her mother’s condition and her mother’s symptoms:

We didn’t know what was going on, and she was going to doctor after doctor after doctor. None of us really knew that it was as bad as it was going to be. We’re just like, “oh she hit her head” and we all just kind of put that aside, and just kind of, waited to see what the doctor said (line 103).

As Penny alluded to, while in this period of uncertainty, it was nearly impossible to anticipate what would happen next immediately following the injury.

However, this did not stop most participants from trying to predict the outcome and attempt to prepare for it. This allowed the participants to cope with uncertain outcomes, even if it did not change the condition of their parent. When many of the questions about the parent’s condition went unanswered, the sense of uncertainty
deepened to continue to frustrate the adolescent. Penny stated with considerable force in her voice:

Six months later, she started getting really really dizzy again. She had gone in for all of her treatments and stuff, and none of them were working, so she went to like… I don’t know how many different therapists she went to physio for it (line 131).

As a result, when the experts’ were also uncertain about the condition, the participants could not help but feel frustrated and irritated with the situation as the symptoms continued to persevere and, at times, dominated their lives while they continued to wait for some result. Jason admitted:

Because, when she was in a coma it was always in the back of your mind that she’s still in a coma. So you never really give 100% to anything, you never really commit to anything because there’s still that one commitment that is the biggest. So once that ended, you could start, you know, going after things and start doing things and whatnot again (line 416).

This kind of uncertainty plagued the adolescents’ minds resulting in a lack of focus and a sense of dwelling on the issue.

Uncertainty was also triggered by a great deal of waiting. Jason described an almost torturous wait for his mother’s condition to change:

Well, because my mom was in a coma for like eight months. So it was kind of the hardest part was, like thinking that she wouldn’t wake up. So, that was the hardest part. Like, it wouldn’t ever get better. It just stayed the same. And nothing would get better (line 193).
Similarly, Tammy stated, “There was me, my brother, my two aunts, my grandma, and my uncle. We were crammed into this little itty bitty room with three chairs. Waiting and waiting and waiting. It was horrible” (line 159). She also explained the need to be re-assured following the accident because of the sudden increase in uncertainty:

We couldn’t go in and see my mom yet. And so it was dealing with the fact that, ok, my mom is in the ICU and my aunt can’t even identify her. She had a hard time because the swelling was so bad. And then it was, they were trying to find my dad and my grandpa and trying to find out what happened with them and where they were and then finding out that (they passed away). It was like, you know, I want to see my mom now. Like I need to go see my mom (line 150).

In a way, this was Tammy’s way of attempting to regain some sense of hope and stability.

As much as these adolescents did not want the worst case scenario to occur (i.e., death of their parent), many admitted that this would at least be a change and a release from the limbo of uncertainty. As Tammy explained, any information from the doctors about her mother’s condition was always a conditional statement making it increasingly difficult to hope for the best case scenario while waiting for the outcome:

If she comes out, she may be a vegetable for the rest of her life. If she comes out, she may not know who she is, what she does, who any of you guys are. She’s not going to know anything (line 387).

The need to be released from this uncertainty became overwhelming for many of the participants and me as we attempted to cope using the resources that were available to
them. Unfortunately, for many, this meant they were constantly thinking about the status of their parent, which required some form of distraction.

Finally, when uncertainty ended, the participants all described feeling suddenly released from limbo because they had some answers to their many questions. Furthermore, the participants described feeling like they could now rejoin society. Jason said it best:

But mostly, when my mom woke up, it changed. Like, you change and you start going back to the person you used to be. Like you do the same things, you start getting excited over the same things and you actually participate and you’re actually there for family conversations and stuff, not kind of wandering off… Because, when she was in a coma, it was always in the back of your mind that she’s still in a coma (line 409).

This period of uncertainty continued for many participants until they witnessed some progress in their parents’ condition. For others, this uncertainty continued until their parents’ brain injury symptoms became stable or mostly constant.

Feeling unheard and disregarded. All the participants alluded to or directly stated feeling like their opinion did not count or that they were left out of many important communications about their parent. This theme related to how the participants were sheltered from the reality of their parent’s injury and not provided with sufficient information to understand the change in their parent. Rebecca described feeling excluded and disregarded while her father stayed in the hospital:

I felt like my voice wasn’t being heard. And like, how I was feeling wasn’t being cared about. (School Guidance counsellor/teacher) and the family I lived with for
four months after were those people for me. And I think that that’s probably the
most important (line 840).

Therefore, the participants sought sources so that they could feel heard. For some, this
involved finding other ways to express themselves, while for others, it meant talking to
other supportive sources in an effort to better understand what was happening to them
and their family.

As a result of little communication from their family members or professionals,
the participants described feeling distant from their parents or family because they had
not been included in the familial process of coping with this major life event. Jessica
stated several times throughout the interview that she felt distant from parents because of
the lack of communication as demonstrated here:

I think they told my mom what to expect after surgery. I’m pretty sure they did.

We just weren’t thinking about it at the time, and we weren’t really, like, dwelling
into it. Like, my brother and I weren’t really thinking about it (line 336).

As demonstrated in the previous theme, with little information, it was difficult to move
past the sense of uncertainty. As uncertainty persisted and the adolescent continued to
feel unheard, coping became more difficult.

However, when the participants were finally heard and listened to, it became a
helpful tool in being able to cope more effectively. Tammy explained how she and her
brother were constantly excluded by medical professionals only to suddenly be included:

Then my grandma got mad at the doctor. He came and pulled my aunt out of the
room and said, “(Aunt) I need to speak with you.” And my grandma said, “No.
You will speak to her in here. These are (mom)’s kids and they need to know
what is happening. Anything you can say to her, you can say in front of these kids” (line 171).

Being included was helpful for many participants because it allowed them to grow closer to their family members as well as anticipate and cope with the changes in their parent. As a result, the participants could re-develop their relationships with their parents, better understand the injury, and better understand how they can support their parents.

**Complex and conflicting emotional experiences.** Emotional experiences are to be expected of adolescents living with parents with ABI and emotional experiences were reported by all the participants. Interestingly, the participants reported experiencing competing, conflicting, and complex emotions felt at the same time. Rebecca stated it outright, “It was a really emotional time for me” (line 193). Frustration tended to be a prominent emotion that frequently conflicted with what the participants thought they “should” feel. Participants tended to feel frustrated with their parent, family, or general circumstances.

> It’s really upsetting because I don’t know how to make my mom feel better when she doesn’t remember things. I mean, when she doesn’t remember them, they’re gone, like there are parts of our childhood that she can’t even remember anymore.

> It’s really upsetting and frustrating” (Penny, line 154).

Frustration and anger were stifled by the participants who told themselves that they should not be feeling these emotions. In some cases, the participants justified the parent(s) behaviour to discount their emotional experience.

> I would get upset when he would be angry at my mom. You know, but I was a kid, too, and I didn’t realize that he wasn’t projecting anger towards my mom, he
was projecting frustration and he was, you know, she was his main caretaker. So, that’s who, it got let out on and their dynamic is definitely not like that anymore but it was for a couple years. It was hard to see that (Rebecca, line 694).

Similarly, Tyson expressed anger towards his stepfather’s newfound aggressive disciplinary techniques. However, he also demonstrated empathy for his stepfather’s behaviour:

The hardest thing about (stepdad)’s accident for me, there’s two things. The first one where he was screaming and yelling at me and he was freaking out and the next thing I remember is one night leaving our house and just going down to the creek and just crying and crying and wanting it to stop. I remember (thinking) this is nothing to do with me, and I knew that. But I was feeling really abused… That didn’t last, so I don’t hold resentment towards (stepdad). That doesn’t ever come up in my mind when I think about him (line 616).

In an attempt to manage and accept the conflicting emotions, many of the participants, like Tyson, attempted to understand adverse or negative behaviours rather than condemn it.

Other participants would turn their frustration, anger, and any other emotion that they considered inappropriate inwards resulting in feelings of guilt, inadequacy, and sadness.

I really resented her. I didn’t want her to be my mom because I always felt so mad at her because she couldn’t remember things and the fact that my problems were huge and all that crap. I was always quite mad at my mom and I felt like she couldn’t understand (Penny, line 502).
Later in the transcript, Penny stated:

I started feeling inadequate in a lot of ways. Like not able to take care of my mom, not able to be what other people wanted me to be, not able to be hell, liked.

It was just that was a shitty year. That was a really shitty year” (line 658).

Combined with these negative emotions, the participants also described considerable shame and guilt. Penny described her feelings of guilt when she was unable to help her mother as much as she had hoped and the internal conflict that was associated with her limited abilities: “When I’m not able to help her, I feel terrible. When I am able to help her and I don’t… I feel terrible. When I do help her, I feel like I’m not doing it enough” (line 316). This guilt was complex in and of itself. It seemed that participants experienced some shame or guilt surrounding their negative emotions as well. Shame and guilt added to the complexity of the experience as they were feeling not only multiple negative emotions about their experiences with their parent, but also guilty and shameful for feeling those emotions.

Despite differing coping mechanisms to manage the complex emotional experiences including their shame and guilt, most participants described several moments of feeling overwhelmed by the multiple emotions making it more difficult to both comprehend their experience as well as manage their emotions.

At times, they (emotions) would well up into one ball of shit-fit. So that happened quite a bit. There were several times like, at least 3 huge occasions where I freaked out about every one of those single things at the same time… When all those issues would well up at once, it would take me to an extremely dark place (Penny, line 755).
Jason explained that his difficulty with his combined emotions:

Like, sad, hurt, and aggression sometimes. Like everything, every kind of feeling.
And it wouldn’t have changed no matter what I did. It would change for 5 minutes
when someone new showed up at the hospital, but then it would just come right
back. So you always expected it to get easier but it didn’t for a long time.

Interestingly, Jason also described the lasting nature of these combined emotions. There
was little to relieve his emotional experiences except simply coping with and processing
them.

Because of the nature of this emotional experience, many participants described
being triggered by other individuals and their actions. Rebecca described being triggered
by a random event several years after her stepfather’s injury:

I was probably about 16 and I was at an all-night techno rave party with my
boyfriend. We were out in the parking lot and these kids were driving around
with one of them sitting on the hood. I asked my boyfriend to ask them not to do it
and he wouldn’t. They were probably really messed up too and like, at first they
weren’t listening to me and then like, I told them my story in a nutshell and they
were like oh, I’m so sorry. I’m like, don’t be sorry for me! Just don’t do it again.
I broke up with my boyfriend the next day. I thought he was a pussy so I broke
up with him (line 616).

As this was approximately four years after her stepfather’s injury, it is clear that these
emotions did not simply dwindle or disappear. It seems participants found ways to be
able to manage them more effectively. However, it was clear the participants
experienced these complex emotions throughout their parent’s recovery.
Grieving for losses and changes. The participants all described experiencing a sense of losing their parent while their parent was still physically present. The participants described feeling a loss of the relationship as well as the individual that they once knew. Rebecca described starting from scratch in rebuilding her relationship with her stepfather and making an attempt to get to know him again.

We were just starting from scratch after his brain injury. Well, he was starting from scratch, learning how to read, to walk, to talk… In my mind as a child, I kind of thought of him as a whole new person. Yeah, it was really just like, starting a new relationship. He was no longer a father figure to me. He was a buddy” (line 725).

Many participants described mourning the loss of the relationship with their injured parent, and others mourned the loss of the individual they thought they knew.

Most of the participants described a sense of losing their parent without physically losing their parents. As one can imagine, this can be a confusing experience. Jessica stated:

And it’s strange, because it’s like losing him even though he’s like, still around every day. So yeah, that, that part’s really daunting sometimes. I mean, it’s better to some days than other days, but some days, you’ll see a glimpse of who he was, but it’s like, really, I think I’m imagining it sometimes. Like I don’t think he ever reverts back to who he was, but sometimes I just like to think, “maybe” (line 160).

The participants realized that their parent would not be going back to the person he or she used to be before the injury.
He’s kind of a new person… I’m not sure, how it works, like I don’t know if over time, he will revert back to the person he was. I don’t predict so, because it’s been so long, and like, nothing’s really been different since when I was 16 or anything (Jessica, line 176).

Thus, the participants experienced grief for the loss of the person who would never come back with the constant reminder of who they had been right in front of them.

In addition to the sense of losing their parent with an ABI, participants also described a sense of grieving for the loss of their “normal” family and their pre-injury lifestyle, which included friendships and romantic relationships. Penny described feeling the impact of the loss of her mother, her friends, and her boyfriend:

My huge breakdowns were over my mom and then losing a lot of my friends. And then my second largest was again, losing someone that I thought loved me. I don’t know, I think with getting closer to my mom that helped me deal with everything else (line 727).

Participants described experiencing a complex array of emotions in response to their multiple losses in addition to the normal developmental changes in adolescence.

**Signs of accepting the parental ABI.** As the participants all looked back at their experiences, the first two to three years of their experience was the most difficult because they also struggled to accept their circumstances. At this two to three year mark, the participants believed they accepted the major life event that had occurred and acknowledged its permanence. Rebecca explained: “Then it just became acceptance and understanding. And realizing that this is my family and this is who we are and this is what we do” (line 536). Other participants described feeling at peace with their parent’s
injury and having a better understanding of how to cope with changes related to the parental ABI. Penny stated, “I’m at peace with what happened with my mom and I know how to deal with it now” (line 682).

Other participants indicated that although they have accepted most aspects of their parent’s injury, at the time of their interview they had not fully accepted or come to terms with the event entirely. As Jason explained, there will always be parts of the experience that are harder to accept and deal with than others: “I’ve accepted it and probably recently too. I’d put it pretty recently. But I think I’ve got it now. There are still touchy subjects but not like so touchy that you break down and it would ruin your day” (line 662). As such, the participants emphasized that there will always be parts of their parents’ injury that have and will continue to impact their lives in the future, but they all agreed that they have a better understanding of how to manage the situation more effectively.

All the participants alluded to accepting not only the incident and the associated changes, but also the long-term impact that this injury has had and will continue to have on their lives. Some participants said it outright:

I think the thing that made it take so long (to accept) was that you expect that everything will go back to normal. But it never did. It’s as good as it was normally, but it never went back to normal. And that takes a lot to set in. This is the new normal (Jason, line 889).

This concept of new normal was something that most participants said frequently as they described their acceptance of the event. Participants believed that once they had accepted this new normal, they were better equipped to rebuild their lives around this new state of
being. Tammy explained that accepting this new normal was integral in her moving forward in her life.

That’s probably one of the biggest things that I’ve finally accepted. And I guess accepting that it has happened and that it’s not going to go away and, I’m going to live past it. And live with it instead of trying to just, dwell and dwell and dwell and dwell and dwell, and dwell, and dwell, and say “Oh, well one day I’ll get over it”. Like, you don’t get over it. You just move on. And move past it, you live with it (line 642).

Later in the transcript, Tammy described her new normal as somewhere between the pre-injury sense of normal and the post-injury chaos:

I guess it kind of feels like pieces are finally starting to fall back into place. Finally starting to go back to where they used to be and, you know. It’s just never going to be the same as it was, but you know, it’s kind of gone back to normal (line 842).

With the acknowledgement of the changes and the acceptance that things may never be the same, the participants were able to recreate a new sense of self and family.

**Personal growth and development after the parental ABI.** All the participants indicated that they were profoundly changed and were shaped as an adult because of their experience living with their parent with the ABI. This entailed learning important life lessons that have helped them in their adulthood as well as recognizing important traits within themselves that have helped them in their adulthood. All the participants appreciated each day in life and believed that they never take loved-ones for granted. Rebecca explained:
It just made me realize that, like, how precious life is and how you can’t take it for
granted and you can’t take the relationships and the people you love for granted
because in an instant, something crazy can happen, and they might not be there
(line 448).

In experiencing ambiguous loss, the participants believed they were given a second
chance with their injured parent.

In living through their experience with their parent with an ABI, the participants
also were able to recognize their priorities as they were forced to manage their priorities
while also coping with their parent’s injury: “This is what matters in my life: my mom,
my family, and everything. And like, since then, I’ve become … protective of my
family, almost to a flaw at times” (Penny, line 805). This includes what they think is
most important in their lives. For example, Jason explained how he does not allow
external things to bother him as much because he chooses not to let the smaller things
bother him:

You gotta enjoy life, like you can’t get mad at people … I’d regret every time me
and my parents used to get into a fight. Like when I got kicked out for like two
weeks, I regret that 100%. Like not saying sorry and just agreeing to what I did.
It’s the kind of thing that you regret. Being sad is like wasting your time. Like if
you’re going to be sad, it’s not going to change anything, being mad or upset. So
just get over it and be happy. Sometimes you can’t, of course. But, like, for the
most part, stupid little things that bring people down like I just kind of brush it off
(line 549).
As a result of these attitudinal choices, participants also believed that they were stronger individuals than their same aged-peers. This was because most of them believed that they had dealt with an incredibly stressful and upsetting event in their lives, which also provided them with a unique skill set to be able to manage different and unique circumstances. Therefore, all the participants believed that, if needed, more could be asked of them and they could handle more stress than many others who had not had this experience. Jessica explained:

I feel like I’m a lot stronger. And I think I can handle a lot more put on me. Like if another tragedy were to happen in my family or to a friend of mine, I really feel like I could be there to support them. And just through doing more things to, I guess, run away from the problems that were at home, I developed a lot of skills and I met a lot of people, and I grew more self-confident and I became less shy, because I used to be really really shy. But, I really think it helped shape me into a more well-adjusted person (line 500).

Similarly, Tyson stated that he has used his unique set of skills multiple times in both his professional and personal life. He attributes this to his experience with his stepfather and appreciated that he was able to learn something beneficial from his experiences:

I’m pretty optimistic. I’m pretty hard working. I’m loving and I think that these experiences, in some ways, you know, made me stronger and gave me some of the emotional tools. I’ve always felt like I’m a bit further ahead than some people my age… I feel like what I learned from my stepfather, in de-escalating him, has helped me de-escalate cops, the world trade organization stuff I attended in the early (2000)’s (line 710).
Tyson also explained that he used his skills in his professional life supporting individuals with developmental disabilities.

Most of the participants also expressed drawing strength from their parent who continues to recover from their injury. The participants reported thinking of their parent and what they had been through, how they had handled their situation, and telling themselves that they could also be strong, like their parent. When the participants felt a moment of weakness or hopelessness, they would think of their parent.

With everything I do, I always say, well you know, is this the best thing I could be doing? Is this something that would make my dad proud? So I definitely live for that. Living for my mom is, you know, every time I take something for granted I think, would my mom take this for granted. Probably not… I definitely say I’ve changed in a positive way. (Tammy, line 671).

This helped the participants feel confident about tackling their challenges and coping with stressful situations. This further contributed to their overall resilience.

Finally, in addition to gaining valuable skills, self-confidence, appreciation for life, and important life lessons, all the participants stated that they liked how this event had changed them. In other words, all of the participants gained an appreciation for the person they became as a result of their experience living with their parent with an ABI. Jessica stated, “I wouldn’t say it was worth it for my dad to get sick or anything. But I think I really like the person I’ve become because of this. Well, partly because of this” (line 506). Overwhelmingly, participants described that although the experience was mostly negative, there was a lot of positive that came out of it. Penny stated:
As much as you wish this had never happened to your parent, you still, depending on how it fixes things or how it changes things, you still wouldn’t change it, right? So like, as bad as this sounds, I wouldn’t change it because it’s made my mom a lot stronger and it’s made my whole family a lot stronger (line 1046).

None of the participants wished the event never happened. In fact, most of them appreciated that so much good could come of it.

Given the evidence of these themes combined, it is clear that a parental ABI is a major life event that profoundly impacts the adolescent and emerging adult children of the parent with an ABI. Given this critical new development in understanding ABI, I now turn to the impact of an ABI on the family system.

**Parental ABI Changes the Family System**

The acquisition of a brain injury by a parent has an impact on the family system at the time it occurs and on an ongoing basis. In describing their experiences of growing up with a parent with an ABI, the participants described their perceptions of how their family changed following the acquisition of a brain injury by one their parents. This category is composed of four themes: (a) the view of the non-injured parent, (b) the view of the parent with an ABI, (c) changes in family relationships, and (d) changes in family roles and responsibilities. The participants described a pervasive impact on the nature and availability of support within the family throughout the experience and this is reflected in each theme rather than in a theme onto itself. I will describe each theme to demonstrate how an ABI impacted the family system from the participants ‘perspectives.
**View of non-injured parent.** Most participants saw their non-injured parent as strong individuals who would frequently sacrifice their personal well-being for the injured parent. Some of the participants felt that their parent placed most of their priorities on the injured parent, rather than the family functioning or their children. Rebecca stated, “My mom had to make a lot of sacrifices to take care of my stepfather and not to follow the dreams that she wanted to follow. She had to just kind of like, stop her life” (line 330). As a result, some of the participants became the primary source of support for their siblings, and at times, for both the injured and non-injured parent. Tyson explained:

Because I was the oldest son, the oldest child, and my mother worked a lot of hours when I was a teenager, I was deferred to as a second parent. The way my mother communicates with me still and back then was … that emotional support her partner should have been (line 310).

Although most of the caregiving duties fell to the non-injured parent, the main message from most of the participants was that they needed a parent to help them through the event. Unlike her brother, Rebecca believed her mother was a role-model that helped her deal with her stepfather’s injury: “[I think my mom’s reaction to my stepdad’s injury helped me] kind of take that same role in life too” (line 237). This revealed how different the experiences can be for each individual within the same family.

Other participants described their non-injured parent as an individual who maintained the stability within the home by making attempts to keep the family functioning appropriately. In some instances, this meant applying additional pressure to the children to help the household. In Penny’s case, her father applied more pressure to
Penny to financially contribute because she was the only child who could get a job. As Penny stated, “My dad still does it sometimes. He’s like ‘well, you need to get a job to help out around the house.’ And I’m like, well, I’m trying. It’s not like I’m not trying” (line 249). Penny later explained that she understood her father’s intentions and perceived his intentions as necessary to keep the family functioning properly. Penny and Tyson were both expected by their non-injured parent to take more of a leadership role in their family as the eldest children. Both mentioned needing to help the family as best as they could, but also needing their parent to help them cope with their experience.

**View of the parent with the ABI.** The participants recognized the challenges their parents with ABIs experienced as they noticed these changes first hand. One of the most prominent changes that occurred was a decrease in emotional regulation. Rebecca described her reaction to the changes resulting from her stepfather’s injury.

> It was like, he was very child-like at first… He would make really stupid jokes that didn’t make any sense and would cry at the drop of a hat if things weren’t right. Even when things weren’t overwhelming. It was just too much for me (Rebecca, line 472).

As one can imagine, having the parent display more emotion than ever before can become confusing, impacting those observing the sudden display. In Jessica’s case, her father would display both extremes of his emotional experience:

> He doesn’t have bouts of anger or anything like that. It’s just he doesn’t find the same things funny, and he sometimes gets emotional, when before he was never emotional. It’s like things like that. He’s like emotionally closed off at the same
time. Sometimes he’s really emotionally open, and that’s like really unlike him to be, like, either extreme (line 140).

Because this was considerably different from the parent’s pre-injury expression of emotions, the participants described realizing how much the brain injury had impacted their parent’s personality.

In addition, many participants found memory loss and memory difficulties to be hurtful and painful as the parent forgot birthdays and other moments important to the participant. Penny expressed her struggles in accepting her mother’s memory loss and forgetfulness:

That was really hard to deal with… At some point, (my mom) started forgetting things… We would talk to her and she wouldn’t remember and she’d have to say like, “wait, say that 3 or 4 more times” before we could actually get her to remember things. I remember one night she asked me why my sister was so upset. I’m like, well mom, it’s because she’s still really upset about what happened. And then she’s like “what happened?” and I’m like, “well, the girl died”, right? (line 113).

The participants who witnessed this memory loss found it frustrating to repeat themselves frequently, yet they all demonstrated empathy for their parent which led to feeling patient with their parent. As a result, most participants were able to develop incredible tolerance and patience in unusual circumstances.

Other participants were unable to identify a single change, but rather a change in their personality. Jessica indicated that she was unable to identify a single change, but she was able to state the he was “just different.” She further explained:
Like he used to take his work very seriously, that’s what I really remember. Now he doesn’t take it as seriously. Like he doesn’t really take any vacations, he doesn’t really talk about it, he just goes to go. So, he takes like, other things more seriously now, and he finds less things funny, and he’s just, he’s not the complete opposite of who he was, but he’s different, he’s a completely different person (line 153).

In an attempt to adjust to the multiple changes in the parent, the participants made an effort to get to know their parent again. In the process of getting to know their parent, the participants all admitted to recognizing that their relationship with their parent had changed.

**Changes in family relationships.** In reaction to the changes in their parent resulting from the ABI, the participants found themselves interacting differently with their parents. The changes in these interactions were not limited to the interactions between the participants and their parents with the ABIs, but also the interactions between the participant and their non-injured parents, their siblings, and their extended family. Rebecca described her changed relationship with her stepfather as a result of the change in her perspective of him:

We were just starting from scratch after his brain injury. Well, he was starting from scratch, learning how to read, to walk, to talk… In my mind, as a child, I kind of thought of him as a whole new person. Yeah, it was really just like, starting a new relationship. He was no longer a father figure to me. He was a buddy, you know? (line 725)
That Rebecca’s relationship with her stepfather changed from that of a parent and child to that of a friend is a significant change resulting from having to start over again with their relationship.

In some cases, the participants noticed that the type of relationship with their parent did not change, but rather their relationship dynamics were amplified. Participants who perceived their family relationships as strong and close to begin with reported feeling closer to their family after their parent’s injury. Jason stated, “Grandma and our aunt and uncle, like they’re a lot more closer to us too, since the accident. We were close before, but a lot closer now. Especially to my dad’s side of the family” (line 164). Tammy attributed the closeness of her family to the support that was provided to her and her brother from the rest of the family:

My family needed to be together. And that’s what we were. Just all kind of came in and made our own little support group and that was probably the only thing that helped… And that’s probably the only thing that helped me was having a really tight family (line 256).

As Tammy indicated, she and her family created their own support group as they waited for news about her mother. As a result, Tammy and Jason believed that their relationships with their family members had improved. Depending on their experiences being supported by their family members, the support either enhanced or damaged their existing relationships.

Participants believed that their perceptions of family support greatly contributed to the state of their current family relationships. In Tyson’s case, he never considered his
relationship with his stepfather to be a parental relationship, but after the accident, his stepfather attempted to relate to Tyson as a father and disciplinarian. Tyson explained:

…And he would go after me, and try to discipline me but he didn’t really understand what he was doing. He was off and yelling at me and throwing his cane at me, coming down the hall after me. Screaming and yelling, and I was the guy who kept the house together” (line 280).

Tyson’s relationship with his stepfather seemed to weaken after the accident, yet it was not strong to begin with. His experience with his stepfather added to Tyson’s desire to withdraw from the existing relationship with his stepfather, and thus, contributed to the disintegration of the relationship.

Divisions within the family were exaggerated by the parent’s injury. Penny found that her grandmother on her mother’s side was not always supportive with her mother’s concerns, but this seemed to be more so the case after her mother’s injury. Penny indicated that the lack of support for her mother forced her to re-evaluate her relationship with her grandmother in the future.

It’s not the same way we felt about it her (grandma) when we were young. Like, when she comes over, it’s kind of like “oh great what, what’s she going to say this time. You know? Like, don’t get me wrong, we all love our grandma, but (not believing in our mom’s injury and openly saying that) was definitely offensive… There’s no way to prove to her (grandmother) that this was happening (Penny, line 338).

Penny realized that she could not count on her grandmother to support her and her family throughout her mother’s recovery from ABI. Jessica also explained that her parents did
not communicate with her and her brother before her father’s surgery, and this was made more apparent after the tumour was removed:

And now, it’s kind of more like, if she ever tells us anything, like “oh well this, like really funny story your father told me”, and it’s kind of, completely different, than what it used to be. Other than that, my brother and I are still very close and my parents don’t tell us very much as a whole (line 565).

It seemed that pre-injury relationships, positive or negative, became more apparent after the parental ABI.

Alternatively, some participants saw the injury as an opportunity to improve their relationship with their parent. In most cases, the pre-injury relationship was not as positive or as close as the participant had hoped for. Therefore, the participants sought to enhance the relationship once they were given a second chance with their parent.

Well, I remember thinking that because my dad got sick, and he had his surgery that he’d stay home. And like, we could all support him, and I could get to know him better than I did before. Because almost losing him made me really, really want to be closer to him. But, he jumped back into work almost right away. (Jessica, line187).

Similarly, the participants described a change in their relationships with their siblings as they supported each other through their parent’s injury. In Jessica’s case, she and her brother supported each other despite the lack of support or communication from their parents. This helped her feel less alone.

He always listens and he always says, “Oh yeah, I noticed that too” kind of thing. That’s all the support that I need, just to know that someone is experiencing the
exact same situation I am. Because, you know, he’s my family, and he sees everything I see, so you know. So, yeah, it’s been really helpful (Jessica, line 281).

Also, Jason described a change in his relationship with his sister in that they were now equals:

I was kinda like her big brother all the way through high school and then the accident happened and she’s like, my big sister, but I’m still her big brother, kind of thing… she wasn’t really looking up to me anymore… we were looking up at each other (line 127).

The participants all described becoming closer to their siblings as a result of providing ongoing and unconditional support for each other, thus enhancing their existing relationship.

**Changes in family roles and responsibilities.** As family members gained more responsibilities and ways of interacting with each other changed, the roles within the family of the participants seemed to also change. In some cases, existing roles were amplified as the participants gained other responsibilities. Penny described being protective of her family before, but her role in the family as the protector was amplified after her mother’s injury:

If something goes on with my sisters, I get like crazy protective of them. Think of it as a momma cougar if you will? Something happens to my sisters, I am nothing short of unaffectionate to the person whose causing the problem. If someone said anything to my mom, again, nothing short of unaffectionate. Someone says anything about my dad, I spaz (line 811).
Penny saw her role as imperative as the eldest child in the family. She wanted to ensure her family was safe after her mother’s injury to lighten the load for both her parents. This was Penny’s way of caregiving for her siblings.

These role changes were viewed as necessary in light of the changed abilities of the parent. Tammy described thinking that she had switched roles with her mother: “It was almost like, you know, the roles had switched. It was weird” (line 568). Jason also described taking on his father’s role after his father had passed away in reaction to his mother being unable to complete her role within the family:

I took my dad’s (place)… So like, a light bulb needs to be changed. I do that. The deck needs to be painted. I do that… the first time (that happened), I was kind of like, “no, I don’t want to. Like, that was his job.” But if he was still here or he passed away of old age, he’d want me to do (these things for him)” (line 748). Jason assumed his father’s role to take care of his family as best as he could because of the loss of his father as well as his mother’s injury.

As the parent recovered, the participants reported that the roles in the family seemed to shift again while the parent attempted to take his or her pre-injury role back. Tyson experienced a sudden shift twice. The first shift occurred when his stepfather went into the hospital and his mother went to live in Calgary to care for him.

So me and my brother lived by ourselves for six months, there’s a tab at the local grocery store for us, and I had no idea how to shop for food, but I think we spent way too much money and then my mother couldn’t pay it. I didn’t like, I mean, you would get everything that you would want as a teenager (Tyson, line 255).
Tyson reported that he had to take on a leadership role that he had to take on before when his mother was single. Therefore, taking on his leadership and caregiving role was not difficult for him. However, for Tyson, the family roles shifted a second time when his stepfather returned to take back the leadership role despite his existing difficulties.

He really went after me. At first, for the first month, he cried all the time because his medication was making him so emotional. And then when he started to get more ambulatory, he was trying to discipline me like he was my father, which he was my father. He wasn’t actually in that role before (line 277).

The suddenness of these role changes seemed to negatively impact how the participants were able to adjust to the overall experience of the parental ABI because they were coping with not only their parent’s symptoms, but also with their new role in the family.

In addition, the pre-injury role seemed to also impact how the participants were able to adjust to the role shift. The more drastic the change, the more difficulty the participants seemed to have with their new familial roles. Tammy described her difficulties switching into “mommy mode” when she would provide care for her mother:

It was really, really hard, you know, to realize that this, this woman that’s raised me, now I have to help (line 516)… Like it was hard, and it, at the first little bit it was, you know, exhausting. I would get home and all I would want to do is go to sleep because it’s like, I’ve been taking care of my mom all day… but I guess, at the end of the day, it’s my mom. So I have to do that. I think, you know, it’s my mom. I gotta help her out in every which way I can. So, I don’t know. I mean, it was difficult and it was frustrating, but you just kind of do it (line 530).
Many participants attributed their maturity to the sudden and ongoing shifts in roles and responsibilities in the family.

**Parental ABI and External Supportive Resources**

Family support was the first point of access when the participants sought support. However, based on their experiences demonstrated in the above category, all the participants reported seeking support from various external sources supplementing the support or lack of support from their families. The participants described two main sources of external support: (a) informal supports and (b) formal supports. These themes are presented in the following section along with the corresponding sub-themes of helpful and unhelpful supports. The participants voiced their need for more formal supports and this is reflected in an additional sub-theme under formal supports.

**Informal supports.** Participants expressed relying heavily on their friends and their communities for support as they navigated the experience of living with their parents with ABIs. However, like many other forms of support, some participants had both helpful and unhelpful experiences when requesting support from these informal sources. Therefore, this theme has been divided into two subthemes: (a) helpful informal supports and (b) unhelpful informal supports.

**Helpful informal supports.** When some participants were unable to get the support they needed from their family, they sought support from their friends to supplement the support from their family members. Tyson explained his gratitude for the support his friends were able to offer:

I had incredible friends, as I always have had. And some of those incredible friends that I had that year are actually some of those friends I had today…
Between my sister and my brother and I, we built a really interesting extended family (of close friends). Those friends and those family friends and the church friends, I mean people were helpful (Tyson, line 557).

Like Tyson, other participants found this support from close friends helpful. In my case, my friends were the most supportive element of my social support circle as I had few family members who were able to support me or who understood the experience.

As friends were able to provide supplemental support, the participants felt comfortable to approach their friends with both good news and bad news. By sharing their experiences with their friends, some participants found that they had someone outside of their family to celebrate or mourn with, making the experience less difficult. Jason explained:

You gotta tell them (good friends), and your excited to tell them because she’s getting better. You’re not saying she’s still in a coma. She’s learning how to walk, right. She’s going swimming, like, she’s building something with our aunts. So there’s, that was fun kind of thing (Jason, line 495).

When family and friends were unavailable for providing support to the participants, they sought support within the community. Some participants found that support from the community was immensely helpful. Rebecca described receiving support from the community at the beginning of the experience that fostered her sense of hope:

Because I’m from a small community, a lot of kids that I went to school with, like their families were like, sending notes with their kids to school for me or stopping me on the street and just saying “if you ever need anything we’re here for you.”
… It was really sweet actually. It made me feel good that I lived somewhere like
that. (Where) people went out of their way to care (line 425).

Jason had a similar experience with the parents of the hockey players he played hockey
with: “Seeing them in the street and their asking you how you are doing and you tell
them, and they tell you that they are really proud of you. Just little things would help”
(line 624).

Other community support involved becoming part of a community organization or
institution like a church. Tyson described feeling supported by a church that he and his
family became a part of at the beginning of his experience with his stepfather:

So these people (followers of a specific church) are helping our family and this
church community is helping my mother and their paying for things and it’s nice.
It’s what Christians should do, or what people should do… (I gained from the
experience) fellowship. You know, and the worship of something larger. They
said that there was a revival happening and so there was a lot of high energy. So
that was fun, and it was good (line 442).

Tyson explained that his experience with this specific church was exactly what he needed
at the time. He left the church when his beliefs no longer aligned with the beliefs of the
church. Like many participants, Tyson found that being a part of a community
organization or institution helped him feel a part of something rather than being
segregated and disconnected from the community.

**Unhelpful informal supports.** The participants also had unhelpful experiences
when accessing informal supportive resources. Unfortunately, some participants were
met with challenges within their friendships that either created more stress or resulted in a
lack of support. In these cases, participants referred to their friends as being unable to understand the magnitude of their experience and unable to support them in the way that they needed. Rebecca elaborated:

> It was right before school started and I hadn’t seen a couple of my really close friends in a little while and it was really tough trying to explain to them what happened. And making them understand the severity of what happened. How much my life just changed in one minute… Some of my friends had a really hard time giving me the support that I needed as a friend because I was really emotional and I was really up and down. A lot of my really close friends, we ended up fighting. You know, I first went to live with my best friend and her mom and brother. It didn’t work out because she was jealous of how much attention her mom was giving me (line 354).

Furthermore, some of the participants reported experiencing peer rejection as both a characteristic of adolescence as well as part of the experience of living with a parent with an ABI. The parental ABI became another reason to be rejected by some peers.

> Well I had this friend and she knew that I had been going through a really tough year and everything, but she still wasn’t supportive. I think because I didn’t show a lot of interest in her problems, she got into her mind that I was racist. I lost most of my friends in high school because of this (rumour) (Penny, line 625).

This resulted in Penny having few sources of support outside of her family.

The participants who sought support from their communities also noticed that the community occasionally promoted rumours and whispers. Rumours and whispers were viewed as a consequence of accessing support within their community including
community leaders who were close with their parents, people involved in community institutions or organizations, or other individuals who were familiar with the family.

Tyson explained:

Some of the gossip around town was hard. Because (stepdad) had been known through (small town Alberta) for a long time and he’d come in and out of town over his life. Everyone knew my mother, she was very active. So you know, dealing with whispers, you know? And maybe (the whispers) were more innocuous than I thought they were at the time, you know. And people were actually just being concerned and not knowing what to say. But you’re hearing it, because they’re standing four feet away from you at the grocery store (line 649).

As Tyson described, the community involvement was unhelpful at times because the community seemed to stigmatize the parental ABI.

Rebecca also described her experience with families who knew little about the experience and the extent of the changes within her family that were necessary. In reference to her increased responsibility at a young age, Rebecca stated that: “I think a lot of families that were a little bit, you know, more well-off than mine, liked, looked down at my mom for doing that (giving more responsibility) to us” (line 573). Tammy indicated that her first day back at school was particularly difficult because her peers frequently approached her about the accident involving her parents: “And the first day back (to school) was the hardest day of my life. People would come up and say, ‘oh I’m so sorry!’” (line 341). These experiences in the community were unhelpful because the participants viewed these events as adding to their stress rather than alleviating it.
**Formal supports.** All the participants had some experience with or thoughts about formal sources of supports such as medical professionals, rehabilitation specialists, therapists/counsellors, psychiatrists, guidance counsellors, teachers, and social workers. Because of the varied experiences, this theme was divided into three subthemes including (a) helpful formal supports, (b) unhelpful formal supports, and (c) the need for formal supports.

**Helpful formal supports.** Some participants reported positive and helpful experiences with some professionals. Being included in the recovery of their parent seemed to be the most helpful for those participants who had this opportunity. Some participants highly regarded the medical and rehabilitation staff that provided encouraging, yet realistic, support and information. Tammy explained:

> Once a week we would sit down and have a conversation with the neurologist. And he would explain to us, you know, this is the state of your mom’s brain, and he would show us brain scans and explain to us which parts have damage and which parts are considered dead, severe, or minor. So he was awesome and he would tell us that this was probably what you can expect. And he said, “I’m always going to give the worst case scenario”. So you know, any improvement was always, always positive. The doctors were always very happy to hear about, you know, what’s been going on (line 453).

Tammy and Jason both stated that being given the worst case scenario was helpful because they were rarely disappointed. Some participants indicated that the information provided by some medical and rehabilitation staff was helpful as it helped them understand the extent of their parent’s difficulties.
In addition, being permitted to be included in the rehabilitation process and exercises was helpful for participants. Rebecca stated:

Being involved in the rehabilitation process, I think, is really important too. Maybe not on a complete level but, like I would go to my dad’s arts and craft rehabilitation class and I’d also do his physiotherapy. I think that’s really important as well. Trying to understand it and come to terms with it. It also, I guess, gives you a little bit of rehabilitation as well (line 865).

This allowed the participants to become familiar with their parent’s recovery journey, thus allowing the individual to both accept and adjust to their parent’s injury.

Other participants sought more accessible services that were helpful including support from teachers and guidance counsellors. These sources were at times more valued than other formal sources of support because of their accessibility as well as their ability to connect the individual to other helpful resources. Jessica also found support in her teacher whom she trusted:

I told my Humanities teacher what was going on, but not the whole story or anything. She was just really helpful. I really trusted her just because, before I even talked to her, I really liked her as a teacher and as a person, so I felt like I could kind of open up to her. And that really helped me. It was nice to tell another adult… It was nice to have a more adult perspective when you’re 16. But yeah, that was really helpful (line 484).

Some participants sought support with their guidance counsellors at high school. In some cases this was helpful.
My English teacher who also happened to be the school counsellor was really, like, he had a hawk’s eye on me. Any time he thought I was about to break or if I even just looked a little upset, or even if I looked really happy, he would always just call me into his office to talk. He would just let me talk. Which was really good… he was a good support for me when that was all happening (Rebecca, line 443).

These formal sources of support were helpful and appropriate for the participants who had accessed them.

**Unhelpful formal supports.** The participants also reported many negative experiences with formal supports. Unfortunately, these included individuals from multiple professions including those mentioned in the previous theme. Most of the participants reported that many professionals ignored them, resulting in the participants feeling unheard, not listened to, and discounted. Furthermore, the participants described thinking that few or no professionals understood their experiences with their parent. This experience was typically paired with pre-existing perceptions of the professionals, usually therapists and counsellors. Jason shared his pre-existing perceptions of counsellors, which were later reinforced:

> If we had found a counsellor that maybe had been through the same stuff and knew like what to say and all that kind of stuff, sure. But, like most of the time, it seems like counsellors are sometimes pushy. Like they want you to say what’s on your mind. But even if you’re not ready, they want you to say it. Sometimes it’s not the right time. (line 274).
The experience, thus, reinforced the pre-existing perceptions of these professionals making future access to these supports difficult. Tammy shared very similar perceptions, and after her experiences with multiple counsellors, Tammy stated: “You go and talk to a complete stranger, and it’s like talking to a brick wall” (line 297). Unfortunately, this was a common sentiment across all the participants who had accessed counselling services.

Another complaint that many of the participants had was about the timing of the intervention with a counsellor, social worker, or medical professional. Most participants described that the intervention of a professional was often when the individual did not feel ready to talk about their experiences. Tammy stated:

I’m not ready to talk, I’m not. I don’t want to talk. I don’t want to see you (Counsellor). So just close the door… Let me just go through this on my own and what I kept saying to my aunt was when I want to talk, I’ll go find someone. But I don’t want to talk, so stop forcing me to go see these counsellors. Because I don’t want to talk to them (line 264).

Readiness is an important part of the therapeutic process and the participants found that they needed time to acknowledge what had happened to them and their family before they could think about talking about it.

Finally, the participants all described only having access to counsellors who they believed to be improperly trained in helping them with their unique experiences with their parent with an ABI. Penny described an incident in family counselling where her mother was told individually that it was her fault her family was in disarray:
My mom feels that they (counsellors) pass too much judgment on her. Because, I mean the last one said that she wasn’t a good mom and I think it was actually after her accident… And she felt really bad. And they said that it was her fault, and then she said that anything that’s going on with the family is because you’re not dealing with yourself enough… So, she started to try and keep her problems to herself, even though that’s one thing that you can’t keep to yourself. And that’s something you need help with. I think that was one of the better things that my family really got together on – was helping my mom realized it’s not her fault she hit her head (line 1199).

This single event created more harm within the family and impacted the overall functioning of the family.

Some participants felt that some therapists were pushing for their own agenda rather than addressing the concerns of the participant. Penny explained her experience with a school counsellor who had a clear agenda and had little flexibility in the support that he could offer:

Because of what happened with (girl’s death), there was this guy who was brought in. He was a grief (school) counsellor. I know that me and my sisters went to see him but I remember trying to talk to him about my mom, but he kept trying to push the (girl’s death) ordeal first. I was trying to get that off my plate first, which … like, as much as it did affect me, I think my problem was more with my mom (line 305).

Penny stated that she felt invalidated and she also felt that few were willing to listen to her experiences, challenges, and struggles with her mother. Incidences like those
described by Penny, Tammy, and Jason, indicate that some therapists are not aware of the uniqueness of this experience and are more likely to make choices in session that could result in harm.

All the participants had the same recommendation. They thought that they would be more comfortable to talk to a counsellor who was familiar with parental ABI. Jason stated, “If there had been like a counsellor that maybe had specified and was amazing at like, just that field (ABI), that probably would have helped a lot, and take it really slowly” (Jason, line 274). Tammy also indicated that she was only able to access grief counsellors. Although she was experiencing grief, this type of support was not what she needed:

I was back at school and my school principal had told me that the Rockyview Hospital offered free grief counselling. And so I went there. I made an appointment and I went there and I talked to the lady one time. And I didn’t go back. And that was the last person I ever talked to. I felt as though I didn’t need it. That wasn’t the kind of support that I needed. And that seemed to be the only thing out there for support was grief counsellors (line 275).

Because of limited access, inappropriate forms of support and interventions, and negative perceptions and experiences, the participants generally found that many formal supports were unhelpful. Therefore, they relied more heavily on their informal supportive resources such as family, friends, and their community.

The need for formal supports. Overwhelmingly, the participants reported thinking that formal supports such as support groups and accurate and specific informational resources were lacking in the community. The most commonly requested
support was a support group for adolescents living with their parent with an ABI. There are multiple reasons for this. Many participants stated that they needed to know that their experience was not unusual. Furthermore, the participants needed to know that they were not the only children experiencing this phenomenon. Tammy explained:

(The support I needed was like) what my family was to me. So we all kind of had the same amount of emotions and stuff like that we could all talk and help each other get through it. So, if there was like, you know … a support group.. And you know there were support groups and stuff, but they’re all with older people. And there’s nobody at 17 years old and my aunt kept saying to me that, you know, not a lot of people go through this at 17 years old. That’s why there’s not a lot of groups. And I was like, yeah, but people still go through it. I think that probably would have been the most help, is other people (my age) who had gone through it, who had felt those emotions (line 282).

The need to relate to others their age that had experienced the phenomenon was clear. The participants also indicated that support groups would be helpful simply for the support and validation of their experiences outside of the family and their friends. Rebecca stated:

There’s the AA support group. They also have a support group for teens or kids, you know. It’s the same concept because people need to know that there is someone else out there that’s going through the same thing. It gives them a chance to talk about what they’re feeling and what’s going on. I think I was really blessed because I wasn’t a shy kid and I wasn’t an introvert. And a lot of kids are,
and don’t know where to turn and don’t know how to talk about what they’re
going through (line 903).

The need for an adolescent support group seems to be the resource that the participants
would take advantage of because of their need to relate to other adolescents with similar
experiences.

In addition, some participants indicated that many professionals provided little
communication with them or informational resources. Because this was such a concern
for him, Tyson made a request to future service providers:

That’s the first message to service providers: Provide real service because the
whole family is affected by this… they (youth) need to be provided with
resources. I’d say that these kids actually had some real resources and not just a
little pamphlet like I read. They need to use them and communicate with people
about your needs and to not hold any anger (line 773).

Furthermore, few of the participants were included in any informational exchanges with
medical professionals because of their age and relationship with their parent (i.e., they
were under 18 years of age and they were the child of their patient). Jessica described:
“Only the brain tumour was diagnosed. Like, they didn’t really tell us what could happen
after it was removed. Or maybe they did tell my parents, but I wasn’t let in on that” (line
27). Jessica found this lack of knowledge and communication very difficult as she was
constantly dealing with uncertainty.

The overall consensus from all the researchers was that the youth needed some
form of guidance and information to help them better understand what was happening to
their parent, their family and themselves. Jason described his need for someone who could act like a parent to guide him through the experience:

Being the oldest (was not helpful). (It would have been helpful) having someone; like I know it would never have happened, but having someone there that has been through the same thing or almost the exact same thing that maybe I wasn’t related to. But someone who’s been through the exact same thing and that knows exactly what you’re going through. I think would have helped so much… who knew what to look forward to and knew when to talk and knew what you were going through and how to go through it. And could give you advice that would work (line 797).

The participants acknowledged that they managed to cope well enough to get through the experience, but there may have been others that may not be as resilient as they were. Therefore, each participant indicated the desperate need for support for these children as they are often forgotten.

**Personal Coping with Parental ABI**

The acquisition of a brain injury by a parent results in a myriad of changes for the adolescent and emerging adult. Given limited family and external supports available, to them, the participants described how they of necessity drew on their own existing ways of coping and developed new ones to help them through the experience. The participants revealed several unique ways of coping that contributed to their overall resilience during a stressful life event. This category is composed of seven themes: (a) tackling the problems, (b) tackling the emotions, (c) avoidance and distraction, (d)
compartmentalizing stressors, (e) maintaining a sense of normalcy, and (f) optimism and hope. I will describe each theme in the following sections.

**Tackling the problems.** Some of the participants decided to tackle the stress resulting from the unknown and uncertain elements of their parent’s injury using direct means to eliminate some sources of stress. Some participants chose to conduct their own research using the internet to inform their parent’s diagnosis and experiences. Unfortunately, the participants reported feeling unfulfilled as the resources that existed were insufficient or uninformative.

I remember it was like 2 o’clock in the morning and it was like a couple weeks after it happened that I was researching vertigo and everything and, I just kept reading it and I kept getting really mad at it because I was like that’s not what is happening to my mom, you guys are all wrong (Penny, line 445).

The participants also reported finding some of the information inappropriate or unhelpful resulting in some participants experiencing negative reactions. Tammy explains her experience investigating the grieving process to help her through the process:

The thing that bothered me the most though, is that every time you type in grief help in the search bar or grief counselling, like, the first five sentences are “if you are experiencing or even thinking about bodily harm please contact the suicide hotline” and, you know, I never thought about that, but seeing that everywhere I looked and everybody saying “And here’s a card for the suicide hotline, just in case”. You know. You aren’t alone and there are people out there who can help you. It’s like, well I wasn’t thinking about that, but now that you give me this card, now I am (line 308).
Despite the efforts to help the public and prevent harm, this kind of repetitive message was actually more harmful as it triggered Tammy’s thoughts of suicide and self-harm as a means of escaping her current situation.

Other participants made an effort to become familiar with their parent’s difficulty and diagnosis by having conversations with the parent or becoming engaged in their treatment. The participants found this helpful because they were able to rebuild the relationship with their injured parent while also becoming informed about their parent’s recovery process.

I think I hung out quite a bit when he was going to the arts and crafts rehab at the hospital. And I think that was a really a great place for me. Like a starter for me to figure out how to help him, and how to get on his level, you know (Rebecca, line 713).

This seemed to be an effective strategy for Rebecca as she was able to help her stepfather at home and got to know her parent again. In taking a direct approach, a problem-focused strategy seemed to both be helpful and unhelpful. However, most researchers took a different approach.

**Tackling the emotions.** The participants reported needing a way to cope with the emotional impact of stress. Some of the participants had difficulties managing their emotions at first, which resulted in emotional outbursts. However, Rebecca described learning her lesson about emotional expression:

I consider myself a pretty smart person and I think that, when I did lash out towards people or have like a crazy emotional breakouts, that it didn’t feel good, you know. So I realized that’s not how I need to be processing this. I learnt how
to just talk about what was happening inside my head and in my heart rather than
lashing it out or holding it in and then freaking out on someone. I’m really good
at communicating with people when I feel like they’ve stepped over boundaries or
if they’ve hurt me in any kind of way (line 548).

Because of their experiences in adolescence living with their parents with ABIs, the
participants recognized that the coping strategies and skills they had developed were used
later in adulthood. As part of this new found ability, all the participants turned to their
family members, friends, teachers, or other important adults in their lives for social
support.

In some instances, social support was not sufficient or helpful enough to alleviate
and manage their emotional experiences. Some participants reported using various
outlets to help them manage their emotional experiences by expressing and processing
their emotions safely while also providing a source of distraction. Penny described
delving into multiple creative projects that allowed her to process her experience
indirectly.

I also started writing books. I know it sounds stupid to say you write books or
your write poems, but I started writing stories because during these times that I
was really at the lowest times, like, what you said, and I was really upset, I would
start to draw from little parts of my life and all these things, and I had put it all
into a story (line 857).

Like, Penny, Tyson also turned to becoming more involved in drama in high school
where he was able to become part of multiple drama productions in his final year in high
school.
I decided to not go to college and go back to high school for another term because there was some exciting theater stuff happening so I dropped grade 12 English to go back and take Grade 12 Drama actually and work on this play. Then go to more raves, and work at (work) with my brother and my sister and then in the spring, I went to Quebec to do French Immersion (line 541).

Tyson reported finding his drama work helpful in allowing him to distract himself while also being able to effectively process the experience with his stepfather using various plays. These outlets were helpful because they could provide a community outside of the home to prevent isolation and constant dwelling on the circumstances. Having an outlet outside of the home allowed the participants the space they required to cope with, adjust, and accept their parent’s injury.

**Avoidance and distraction.** Using distraction and avoidance allowed the participants to postpone coping until they could effectively process the stressor and determine a course of action. The combination of all the stressful events resulted in the participants feeling overwhelmed.

The first two years was like there was just so much to get used to that you kind of like ignore it some days and then you really dwell on it. One thing that you start doing is a lot of self-pity (Penny, line 462).

Therefore, the participants attempted to ignore or avoid coping with some stressors because there were too many other stressors with higher priority. In some cases, this meant ensuring other family members’ well-being before their own. Penny explained:

I don’t know when I worry about a lot of other people… think about them and then I think about how I’m not doing enough for them… I’d start worrying about
other people’s problems and not my own. I started not caring much about myself and my appearance and everything (line 247).

Penny found that she was able to draw strength by reminding herself that others are coping with this same phenomenon, and that they were having more difficulties with it than she was:

My problems aren’t as big as other people’s are. That’s when I started the whole, everyone before myself, kind of thing. I’m still very lazy at home, but I definitely feel less guilt than I did before about not helping out (line 476).

By focusing on others, Penny tended avoided her own concerns until she was sure that her family members would be okay. This was Penny’s way of taking care of her family, but it was at the cost of her personal well-being.

In other cases, the participants used distraction and avoidance because they believed they could not manage their stressors and the feelings of stress any other way. Jessica explained that her avoidance of her home environment helped her cope with the first couple of years because the situation at home was not within her power to change:

I kept myself really busy with school and extra-curriculars. I stayed late at school a lot. And if I had to go home, I would just find a way to stay at a friend’s place because it was just so hard being home (line 289).

Although distraction and avoidance are typically not helpful, especially when there are other coping mechanisms available, distraction and avoidance coping strategies were effective in that the participants were able to manage multiple stressors.
Compartmentalizing stressors. Compartmentalizing was a key strategy used for managing multiple stressors, especially when the participants were feeling overwhelmed. All the participants had multiple stressors to cope with at the same time that required significant resources. Although many participants avoided some stressors, they also found that they were able to consciously cope with one stressor at a time using one of the aforementioned coping strategies.

If one thing started bothering me, I’d start thinking of something else. Like, I gotta do this for someone or my mom. And I’m like, well my mom’s really hurt and that starts bothering me and I’d switch immediately to something else. So, it was a lot of avoidance, but dealing at the same time. So it was like my way of dealing with it is to just be like, “you know what? This isn’t as bad as this and this isn’t as bad as that (Penny, line 661).

This kind of stressor management was imperative to preventing crises in the midst of this experience. Tammy described using a combination of compartmentalization, mindfulness, and avoidance to manage the stressors in her life and prevent “falling apart”:

I don’t think I really did (manage everything). I think I just, kind of, pushed it all out of my mind. And I got very good at doing that. So I don’t think I ever really coped with all the stress that I was under. I just kind of, made it go away in my head. Just being able to push everything from your mind except for the thing you are doing at the current moment… when I wanted to deal with it, I will deal with it then. But for now, I am just going to push it out of my mind, and pretend like it never happened (line 610).
Compartmentalizing stressors seemed to be very helpful to the participants as it allowed them to cope with their stressors on their own terms, on their own time, and using their own means.

**Maintaining a sense of normalcy.** Each of the participants described a life area that they held onto to maintain some sense of normalcy and stability in their lives. The participant’s described their lives at the time as transitional, and thus, unstable, after their parent’s injury. Therefore, maintaining this normal part of life became an important way for the participants to manage their stressors including their education. Tammy described her school life becoming the one place in her life that was stable and normal.

It was great because it (school) was just that kind of solid part of my life that I can just escape to. Where I knew my thoughts and everything had to be on school and nothing else… you need something solid that’s never going to leave, that is going to be in the same place at the same time 365 days a year (line 360).

This strategy allowed the participants to focus on life areas that they did have control over and improve. In Tammy’s case, she was able to control her performance at school and she focused on making her school life normal. She stated that this was to help her better manage her home life with fewer stressors to worry about.

Similarly, Tyson explained how he managed adversity by making other areas more positive: “I’ve also for the most part charge through adversity all the time. Like kept smiling and tried to hold onto those things that had function in my life and make them work better when other areas weren’t” (line 414). It may seem as though some participants might have been avoiding their stressors by focusing more on other life areas.
However, participants viewed their actions as being proactive as they knew that they were not capable to effectively cope with the stressors resulting from the parent’s injury.

Some participants attempted to maintain normal family activities outside of their families. Rebecca stated that she engaged in Air Cadets to compensate for the activities her family used to engage in before her stepfather’s accident.

With air cadets you know, my family was really active with going out camping and sledding and all that… Now, we’re really limited to what we can do and for a while someone always needed to be home with my dad. So, that was kind of like my replacement, was air cadets (line 521).

This allowed her to create some distance from the family, contributing to her overall sense of independence at a young age. As part of this normal life area, the participants all expressed a need for others in that environment to behave normally to ensure that they could continue enjoying one “normal” part of life. Tammy explained:

I wanted them (teachers) to treat me normal. And I, I guess I wanted that… that balance, and that normality back in my life. Like this is something that’s not going to change. This is school. It starts at 8:10am. It finishes at 3:20pm. And it’s always going to be there. And I just, I guess I just needed that routine back in my life to try and get my mind and get my mind off of only the accident and only my mom (line 349).

This need was strong for many participants indicating that maintaining a normal part of life was important in coping with and managing a parental ABI.
Optimism and hope. The participants all developed optimistic traits to ensure that they maintained their hope while their parent recovered. The participants reported frequently reminding themselves that their parent would improve and that everything would work out for the best. “To kind of look on the bright side of life you know. Like, ok, I don’t have this, but I also have all these wonderful things” (Rebecca, line 244). Other participants reported being reminded by others to maintain their hope and their optimism. As Jessica explained:

Sometimes it just brings me, like, a lot of comfort to hear people say, like, “You know what? Things happen but you’ll be ok.” Even though I don’t believe that myself, sometimes it helps to hear someone, like even older than you, that you can survive and they tell you that (line 484).

These reminders were critical for the participants in maintaining and sustaining their hope and optimism.

Many of the participants also found that their hope was fueled by their optimism as well as other external sources. Tyson explained his initial feelings of hope:

(hearing it was a miracle dad was alive) I think, it gave me a sense of hope in a despairing moment and also a sense of like, that we were moving forward in a way that was going to not be such a terrible outcome (line 179).

Jason explained that when his mother woke up from her coma, he was suddenly hopeful that his situation would improve:

We accepted it (mom’s state) when my mom woke up. Because things actually looked up. Like things started getting better. Basically, it just (keeps) getting better and better and she still gets better. So, it’s still a very slow process but you
know she’s getting better, not worse. So, that’s the main thing. Things are looking up (line 404).

As the participants, witnessed signs of improvement in their parents, their hope and optimism continued to grow.

Finally, some participants stated that their hope for an improved relationship with their injured parent helped them provide the care that their parent needed. Jessica stated: “(After his surgery, I hoped) we could all support him, and I could get to, like, know him better than I did before. Because, like, almost losing him, like, made me really really want to be closer to him” (line 188). Tammy described having a second chance with her mother as well:

I think it was especially the fact that you know, it was my mom that survived. That it was the parent that I didn’t have the closest relationship with. Now, I’ve never been closer with my mom in my entire life. And, I regret never being as close with her. I do. So I won’t ever let it happen again. I value every single moment with her (line 802).

This hope for an improved relationship with the injured parent allowed the participants to provide the ongoing support to their parent in need. Furthermore, many participants also described how their ability to be optimistic and hopeful in seemingly hopeless situations had been helpful for them in adulthood when they encountered other difficult situations. In this way, their hope and optimism as an adolescent experiencing this event had contributed to their overall resilience as adults as well.
Summary

In this chapter, I presented participant profiles to provide a context for understanding the diversity of experiences encountered by the participants as well as their similarities. Then, I presented the findings of the study, which were divided into four categories: (a) parental ABI impacts adolescents and emerging adults; (b) parental ABI changes the family; (c) parental ABI and external supportive resources; and (d) personal coping with parental ABI. Each participant experienced the phenomenon described within all four of these categories to some extent at some point in his or her experience of living with a parent with an ABI.
CHAPTER FIVE: DISCUSSION AND IMPLICATIONS

As an exploratory research study, the intention of this research was to illuminate the experience of adolescents and emerging adult children growing up living with a parent with an ABI. The findings describe the complexity of this experience, which can be understood within the context of the literature; however, these findings also break new ground in understanding the individual adolescent’s and emerging adult’s experience of a parental ABI. In this chapter, I will first share the creative synthesis that integrates all information collected from the participants as well as my own story into a single narrative. I will then discuss the findings within the context of the literature to compare and contrast the literature with the findings as well as to explore new areas. Next, I will discuss the limitations of the current research. Finally, I will discuss the implications for theory, research, and practice in counselling psychology. In this chapter, the term “parent” refers to the parent with an ABI, unless otherwise stated.

The Creative Synthesis: A Group Story

The creative synthesis is a composite of the group depiction, relaying the common experience in a creative manner. Because I am more prone to storytelling, it seemed appropriate to write a narrative that describes this journey. It is important to note that this story will be told in my voice, but it is not simply my story. It is a reflection and combination of those who shared their stories for the purposes of this research.

Group Story: Our Voices, Our Stories

I share my story with you today so that I will be heard. I share my story so I can better understand how I got to this point in life, and so that others know that they are not alone. One day, I was a normal teenager, and the next, I needed to be a responsible,
reliable, and independent adult. I had to take care of the house; I had to take care of my siblings; I had to be financially responsible; I had to suck it up for the sake of my family and for the sake of my parent. Of course, it wasn’t something that happened overnight. But, in many ways, it felt like that’s what happened. My parent acquired a brain injury, and it changed everything. It changed my family. It changed the person I thought I was. It changed the people I thought I knew. My parent’s brain injury was life-changing. It triggered a series of events in my life that made me who I am today.

I was so busy all the time doing everything that needed to be done in the family, that I didn’t have the time to really process what had happened to me, my parent, and my family. At first, I thought things would go back to normal. We had had a blip in the family; now it was time for the things to go back the way they were. I didn’t really understand that there was no way that could happen, so I kept trying to make things as normal as possible in my life. I tried to maintain one life area that I knew wouldn’t change and that I was in control of. I needed stability in a time of chaos, confusion, and uncertainty.

I think a lot of my uncertainty about the experience came from not being included in exchanges about my parent’s condition and not being informed. I would ask my non-injured parent, doctors, and social workers about what was happening to my parent. No one would tell me, or worse, they would tell my non-injured parent who wouldn’t tell me anything. I felt lost and like no one cared that I was part of this family and had a right to know what was happening. I tried learning about what impacted my parent on the internet and how I could help, but that wasn’t helpful. Most of the information wasn’t applicable to me as the child of a person with an ABI.
My home life started to get rockier and more stressful while my siblings, my non-injured parent, and I tried to keep things functioning in the family. I had to take on new roles and responsibilities because my parent couldn’t do certain things anymore. I started taking on more responsibilities. We all had to. This was the only way we could make things work in the family. Eventually, my parent wanted a bit more of his or her old role so I would let it go bit by bit. The challenge was when my parent wanted me to be a child again, and I couldn’t do it. At that point I was no longer a child, nor did I feel like a child.

I felt so many different things after my parent’s brain injury. It was hard to tease them apart to talk about them. Mostly, I felt frustrated and guilty. I felt frustrated a lot because I wanted my parent with the brain injury to stop acting like he or she was and just be my parent again. I felt guilty for feeling that way. I loved my parent. I was thankful my parent stayed alive, but I was so tired of never knowing what I was going to get next. It wasn’t until my parent started to stabilize that I began to actually feel like myself again, whatever that was.

After a few months of being around my parent, I started to miss everything about my life before my parent’s injury. I saw my friends doing things that normal kids would do, and I needed to stay home with my parent, or go to work so that I could pay house bills, or take care of my siblings while my parents went to the doctor. I was happy that I could help and contribute, but I felt like I had to grow up so quickly that I couldn’t join in these normal teenager activities.

I also started to miss the person my parent had been. I felt like I had lost this huge thing in my life, and I felt like I had lost my parent even though he or she was right in
front of me. It was a confusing feeling and I felt guilty for feeling sad about it. It was kind of like I lost my parent in a way. I lost the person my parent was, and I lost the relationship we had. People just kept telling me that I was lucky that my parent was still alive. But I was sad. I had still lost the person my parent was and would never get that person back. I was grateful my parent was alive, but I missed who my parent used to be. I was angry, sad, resentful, and frustrated with my parent because of his or her ABI, and I felt like these emotions shouldn’t exist. These complicated emotions were so confusing for me.

The family environment started to become somewhere I didn’t want to be. My non-injured parent tried to take care of everything, but I think that often meant sacrificing his/her own well-being. My siblings and I started to take care of each other because my non-injured parent needed to care for my parent. We really tried to run things as best as we could, but it was a struggle. I really needed a parent, and I think my siblings would say the same thing. We needed an adult to help us through this whole thing, and my non-injured parent couldn’t do it all.

My parent was just different. I think the most upsetting change for me was my parent’s memory. Sometimes, I would have to remind my parent of really important things like birthdays and events that would never have been forgotten before the injury. I also found that my parent’s emotions were all over the place, and it was difficult to manage. I struggled with that because I didn’t know what to do when my parent would start crying over something little or my parent would start throwing things around when he or she was frustrated. Other times, my parent wouldn’t express any emotion. It was really hard being able to manage the extremes.
My relationships with my parents changed because they had to. I had to grow up quickly so I know I had changed quite a bit too. We suddenly had a buddy-buddy relationship rather than a parent-child relationship. Because my parent with the injury was different, I needed to get to know my parent again. It took time, but I was able to develop a new kind of relationship with my parents. My relationships with my siblings evolved too. We were no longer just siblings; we were friends. We looked out for each other, and I know that they will always be there for me.

I drew a lot of support from my immediate family, especially my siblings. It was like we had our own support group going on because they knew everything that I was going through. But there were times that my family wasn’t very supportive or understanding. I turned to my friends for social support. I tried to get my friends to understand what had happened, but I felt like a lot of them didn’t really get it. Some of them were awesome supports. Others didn’t really know how to support me or even what to say. I can’t say I blame them considering I didn’t know what to say myself. I had problems telling them how much my life had changed, and part of me didn’t want to tell them. I was worried people would treat me differently, and I didn’t want that. Eventually, I lost a few friends because they just couldn’t be there for me.

It seemed a lot of things couldn’t help. So, I started to engage in other activities to distract myself from what was happening at home. I also started to make other parts of my life better like by getting more involved in community activities, in school activities, and with my own creativity. This helped me separate my stressors and deal with things on my own terms. I got really good at compartmentalizing my stressors and dealing with my problems one problem at a time. I still do this today sometimes.
I also talked to a counsellor about what was happening at home and what I was going through, but that wasn’t very helpful. It was almost as though the counsellor didn’t know what to do with me because it was something the counsellor had never dealt with. I didn’t find that the counsellor heard me or really understood what I was going through. I started talking to doctors, or at least those who would sit down with me and tell me what was happening. I talked with important adults like teachers or guidance counsellors who were there just to listen. I really struggled trying to find someone who really got it. I think that was the most difficult part of the experience. I felt alone and like no one else knew what this experience was like. It would have been nice to talk to other people my age who had also experienced being with a parent with a brain injury.

Eventually, I started to come to terms with what had happened. Despite all my distraction and avoidance, I started to realize that my life was forever changed. I started to realize that this was what my life was going to be like. This was the new normal. I had faith that things could only get better, but I knew that things would never be the same. I was optimistic because things kept getting better. I could only hope that things would keep going well. My optimism and hope went hand in hand.

As my parent recovered, things at home started to get better. I think we all started to adjust to things and accepting the new normal. We still had a few kinks, and there will always be reminders that the brain injury is there. Sometimes, my parent stumbles on words, or forgets what I said, or gets more emotional than usual. Overall, I think I can handle it better now than I did then. I feel more prepared to deal with problems related to my parent’s injury. I am definitely a lot stronger than I was.
I know it was a difficult time in my life, but I think I am a better person for it. I learned a lot from the experience and even more about what it is to be an adult. I know more about myself, about my family, and how to cope with tough situations. I am a stronger person, and I am very happy with the person I became. It was definitely hard, and I wouldn’t wish it on anyone. But I am who I am because of my parent’s brain injury.

I know there are more like me and to them, I say that you don’t need to be alone, and you can get through this. It will get better. It always does. You need to maintain hope and find your own strength. Whether it is inspired by your family or by other things that you have gone through in your life, you will make it through because you have to. I am here to tell you that I survived, and you need to know that you will too.

**Findings in Context**

The findings characterize the experiences described by the participants and me. In this section, I will place the findings into the context of the existing research literature as it relates to each category. Following on the presentation of the findings in Chapter Four, I will discuss the following categories and their associated themes: (a) parental ABI impacts adolescent and emerging adults, (b) parental ABI changes the family system, (c) parental ABI and external supportive resources, and (d) personal coping with parental ABI. It is important to note that there is very little research referring to the experience of adolescent and emerging adult children living with a parent with an ABI. Consequently, in each category, I will discuss the findings within the context of the relevant research literature from areas such as disability and brain injury, adolescence, emerging adulthood, family systems, resilience, stress and coping, and any combination of the above areas.
Parental ABI Impacts Adolescents and Emerging Adults

The findings suggest that parental ABI impacts the adolescent and emerging adults in a variety of ways. Because of the multiple changes that resulted from the parental ABI in many areas of life, the participants all reacted in ways that suggest they were heavily influenced by living with their parent. To clarify the impact of a parental ABI, I will discuss each of the themes that compose this category by comparing and contrasting them with the research literature. These themes include (a) ABI as a life-changing event, (b) feeling busy with depleted resources, (c) sudden increase in responsibility leading to a sense of maturity, (d) the uncertainty of the future, (e) feeling unheard and disregarded, (f) complex and conflicting emotional experiences, (g) grieving for losses and changes, (h) signs of accepting the parental ABI, and (i) personal growth and development after the parental ABI.

**ABI as a life-changing event.** Participants believed that the parental ABI permanently changed their lives. Although the participants did not initially perceive the ABI as a life-changing event, they came to the conclusion that their life was forever changed because of it. This suggests that the parental ABI acted as a trigger for changes in the parent, the family, and the participants. According to Goodman et al. (2006), a trigger is an event or non-event that precedes a transition and acts as a catalyst for a transition to take place.

Participants described feeling shocked when they learned of the event that caused their parents’ ABIs. This is consistent with the research literature that indicates that shock is a common reaction for individuals learning that their family member has acquired a brain injury (Charles et al., 2007; Dausch & Saliman, 2009; Doidge, 2007; Kreutzer,
Shock is also a common reaction when individuals are initially processing traumatic events that have impacted family members (Cohen et al., 2006; Kelly & Ward, 2011).

Shock was followed by feelings of uncertainty as the participants attempted to learn about the ABI. Feelings of uncertainty immediately following the event are also considered to be a common reaction when the survival of the family member is unclear (Landau & Hissett, 2008; Rolland, 1999). The participants described being able to recognize that changes needed to occur, but they did not anticipate what these changes would be, the permanence of the changes, or the extent of the changes. This ambiguity contributed to their initial feelings of uncertainty immediately following the ABI, suggesting the participants were thrust into a transitional process. Ambiguity and uncertainty are highly reported characteristics of being in the midst of a transitional experience suggesting that an ABI is the beginning of a major life change (Goodman et al., 2006; Turner et al., 2007; Turner, 2005).

Although the participants recognized that their lives were about to change, they did not anticipate the extent of the changes. Many of the participants described the changes as a world suddenly coming to a stop, while simultaneously having the rest of their lives continue. This kind of contradiction was commonly described by the participants suggesting that they were aware of the life-changing event, yet struggled to make room for this event in their lives. As such, the participants balanced a regular adolescent life with an irregular family crisis to continue their adolescent development and have a sense of continuity as they began to recognize the changes that were occurring.
in their family. Because this is a new area of research, this finding is unique to this research study.

**Feeling busy with depleted resources.** The participants felt drained, busy, and stressed in the acute phases of the parental ABI. This was the result of having to take on more responsibility within the family and constantly have to adapt to the changes in their parent with an ABI and their family while also managing regular, unchanged adolescent lives. Adolescents may feel exceptionally busy when adjusting to a parental ABI given their normal commitments to school, work, and family that are typical of normal adolescent development. As a result, the stress of managing all these changes while simultaneously managing normal teenaged life inevitably increases.

This theme has not been discussed in the research literature in the context of adolescent or emerging adult children living with a parent with an ABI, but it has been discussed amongst the caregiver literature. Orto and Power (2000) stated that adult caregivers tend to feel this sudden drain of resources while also feeling busy because of the sudden increase in responsibilities that are placed upon them. In addition, young carers or caregivers (i.e., children who provide care above and beyond what is expected of their same aged peers) have been found to be at an increased risk of mental health concerns because of their increased responsibilities in caring for their parent with a disability (Aldridge, 2008; Barkmann et al., 2007). It is interesting that the participants who reported feeling busy the most were the eldest children in the family, suggesting that more caregiving duties may have fallen to them given their existing role in the family.

However, feeling busy with a depletion of resources was not limited to the participants with more caregiving duties. The participants who were not the eldest
children and did not take on many caregiving responsibilities in the family also reported these feelings, suggesting that it may be the sudden increase in responsibility that results in feeling busy. This finding is contrary to the research literature that suggests that it is the caregiving duties that result in these feelings.

**Sudden increase in responsibility leading to a sense of maturity.** As alluded to in the above theme, the participants noticed that more responsibility was expected of them within their families. The participants indicated that they also felt the need to support their family in any way they could as part of their duties as a family member. Therefore, the participants would often add responsibilities to their own lives in an attempt to contribute more to the family. Despite their willingness, most of the participants also described feeling unprepared for the magnitude of the responsibility suddenly placed upon them. This is consistent with the research literature indicating that families distribute responsibilities across all family members resulting in children being given roles that are beyond what is typically expected of children (Butera-Prinzi & Perlesz, 2004; Rolland, 1999). The sudden increase in responsibility is also consistent with the moving in phase of a psychosocial transition as described by Goodman et al. (2006); this phase is characterized by taking on new responsibilities as a reaction to the trigger.

As a result of this sudden responsibility, all the participants stated that they felt more mature than their same aged peers because they had to “grow-up.” This was viewed as a benefit of the experience. Although the majority of research literature indicated that this sudden increase in responsibility is detrimental to the child or adolescent, the current research findings are consistent with the views presented in Aldridge (2008) in that the
experience of living with a family member with an acquired disability or illness is not entirely detrimental to the children. Aldridge suggested that children with caregiving duties gain many valuable skills that help them in their adulthood and that contribute to their overall resilience as children and adults. The current research supports Aldridge’s proposal in that the participants described feeling more mature and better prepared for adulthood, suggesting that this increase in responsibility had a complex effect on the adolescents. Although the sudden increase in responsibility was difficult to manage at the time, it was also viewed as a beneficial experience in preparing adolescence for being a responsible adult.

**The uncertainty of the future.** The participants described feeling uncertain about their future, the future of their parent, and the future of their family. This theme included feeling unsure of their identity as adolescents and emerging adults. Participants started to recognize the nature of the changes in their family and their parent resulting in considerable uncertainty about how their lives would be different. As the participants grew accustomed to the added responsibility and busyness of their lives, they began to wonder about their parent’s ABI and the impact of the ABI. As such, the participants started to realize that change was imminent. Uncertainty is a characteristic of the moving through phase of the integrated transition model (Goodman et al., 2006) suggesting that the participants had entered a phase that one participant called limbo.

In addition, the current findings are consistent with the findings of Butera-Prinzi and Perlesz (2004) in that this uncertainty is particularly troublesome for children of parents with ABI. Despite the fact that children may not be included or informed about their parent’s illness or disability, they can sense changes within their family and this
uncertainty is correlated with increased anxiety (Butera-Prinzi & Perlesz, 2004; Rolland, 1999). An increase in stress and anxiety within the family is correlated with poor family functioning (Carnes & Quinn, 2005), poor identity formation (Levitt et al., 2007), and an increased likelihood that adolescents will seek guidance from their peers who may or may not be already considered deviant (Levitt et al., 2007).

**Feeling unheard and disregarded.** The participants described feeling unheard and disregarded in the early stages of their parent’s recovery process, particularly when they actively sought information about their parent’s injury, recovery, or rehabilitation. The participants also described an overwhelming sense of feeling alone, ignored, and unheard as they attempted to resolve their feelings of uncertainty. These feelings contributed to a sense of having little to no guidance and a need for a parent. The participants all described feeling the need for parental or adult guidance throughout the experience, but none of them had received the kind of support they had hoped for. This finding has not been found in the existing research literature, likely because of the paucity of research studies considering the experience of children (adolescent or otherwise) living with a parent with an ABI. Similarly, this characteristic has not been described by transitional literature suggesting it may be unique to this phenomenon.

Furthermore, feeling unheard and disregarded is potentially unique to adolescents because they are considered to be children and are typically excluded from information sharing about the rehabilitation process and recovery for fear of impacting their psychological well-being and development (Florian & Katz, 1991). However, adolescents have the mental capacity to understand the circumstances impacting their parent (Steinberg, 2005). Adolescents require this information about their parent so they
are better prepared to anticipate and cope with the changes that may occur in their family. By being ignored or disregarded in the process, the adolescents may seek guidance, support, and understanding of their experiences from other sources that may or may not be helpful to them (Carr, 1999; Levitt et al., 2007).

**Complex and conflicting emotional experiences.** The participants described experiencing many complex and conflicting emotions as a result of recognizing the changes in their parent as well as their family. The participants agreed that there were some emotions that were difficult to admit to or even share because they believed they “should not” have these feelings towards their parent. Feelings such as anger, frustration, and resentment towards their parent were described in close proximity to the feelings of guilt. Complex emotional experiences are described in the integrated transition model (Goodman et al., 2006) and are believed to be typical of the moving through phase. In addition, the conflicting emotional experiences are consistent with the research literature in that family members immediately reacted to the symptoms of the parent’s injury (Charles et al., 2007; Landau & Hissett, 2008). According to Butera-Prinzi and Perlesz (2004), these emotions are frequently stifled because of the shame and guilt that surrounds the emotional experiences.

What is unique about these findings is that the participants continued to struggle with their conflicting emotions well past the acute phases of their parental ABI. For example, Rebecca often indicated that her mother had gone to live in Calgary to take care of her stepfather with the ABI. Rebecca then stated that she needed the support of her mother at the time, but justified her mother’s actions by stating that her stepfather needed more support than what could be offered by nurses. This finding suggests that some
participants continued to struggle with both acknowledging and expressing their conflicting emotions at the time of the interview. This can be problematic as it can prevent effective processing of the emotional experiences, thus stifling the adolescent’s adjustment to the injury. Although this finding is unique to the current research, it has been suggested as a possible impact amongst children living with parents with ABIs (Charles et al., 2007).

**Grieving for losses and changes.** Although grief and loss was discussed by the participants, their grieving process was not directly identified and named by the participants. Indeed, the participants did not appear to recognize their feelings of grief. Several participants described a sense of losing their parent even though their parent was still present, but they did not necessarily identify it as grief. The participants appeared to experience a sense of psychological ambiguous loss described by various researchers (Boss, 2007; Boss, Roos, & Harris, 2011; Butera-Prinzi & Perlesz, 2004; Landau & Hissett, 2008), only the participants did not have the language to name their loss.

The difficulty in naming ambiguous loss in the experience of living with a family member with an ABI is commonly described in the research literature (Butera-Prinzi & Perlesz, 2004; Landau & Hissett, 2008). This is likely because individuals are not aware that they can still grieve the loss of a person even though they are physically present. Such lack of awareness can be detrimental, especially for adolescents who are already feeling guilty for their emotional experiences, because they may try to disregard their grief in addition to their other emotional experiences rather than acknowledge it and process it. Guilt was frequently described by the participants when they were discussing their loss, as they felt that they “should not” feel guilty because they still had their parent
present. The participants also described feeling a loss of the life they knew before the injury, as well as a loss of their old identity as adolescents or emerging adults. This sense of loss was in response to the immense changes that occurred simultaneously, resulting in recognition that they were forever changed. The fact that participants mourned their pre-injury life like their parent is a finding unique to this study in that no previous research studies have indicated that the children also experience a sense of loss of the pre-injury identity and family. However, a grieving process is characteristic of the integrated transition model (Goodman et al., 2006) when the individual is preparing to leave the moving through phase and enter the moving out phase.

**Signs of accepting the parental ABI.** The participants all described a sense of both acknowledging and accepting the changes in themselves, their parents, and their families as a result of the parental ABI. Most of the participants believed that they started to accept the “new normal” in that they no longer expected their lives to go back to the way it was before their parent’s injury. As such, they started to embrace the changes and accept them as typical of their current lives. Other participants felt they had accepted most aspects of their parents’ injury while other aspects were considered a work in progress. These participants indicated that there were always going to be aspects of their parent’s injury that would be difficult to accept, but they felt better prepared to manage the impact of their parent’s ABI. This suggested that the participants developed a sense of mastery over their new skills, roles, routines, and responsibilities.

By developing a sense of mastery in their “new normal” lives, the participants made a critical step that allowed them to rebuild their lives. When the participants started to accept the changes, they also started to acknowledge the potential for ongoing changes
as their parent’s abilities continue to improve. As such, participants started to create their “new normal” lives around the possibility that their parent might, require ongoing support. In accepting this new normal, participants developed a new sense of self and family. Accepting the finality of the changes resulting from the trigger is also characteristic of the moving out phase of the integrated transition model (Goodman et al., 2006).

**Personal growth and development after the parental ABI.** Although the participants described their experience as difficult, life-changing, and somewhat negative at the time, they also described their immense gratitude for the life lessons, personal growth, maturity, independence, and changes that occurred as a result of living with their parent. This is contrary to most research literature that suggests that these individuals will struggle in their adult years because of their experiences in adolescence that disrupts their overall development (Barkman, et al., 2007; Erikson, 1968; Feldman, McConnell, & Aunos, 2012; Kieffer-Kristensen et al., 2011; Orto & Power, 2000). It seems that most of the research literature has ignored the resilience of these youth in that this experience can be reframed as an event that can improve their development and growth rather than hinder it. As such, these findings are in agreement with Aldridge’s (2008) view that rather than conceiving of young carers as voiceless victims in the family impacted by disability or illness, the benefits for these adolescents and emerging adults must also be considered. These children are considerably adaptable and therefore, resilient because of their experiences (Aldridge, 2008).

As part of this growth, some participants used the parental ABI to redirect their lives and reflect on the kind of adult they wanted to become. For example, Jason
reported being prone to “getting into trouble” with the law, drugs, and alcohol prior to his mother’s injury. However, Jason made different choices, which resulted in his changed direction that he attributes to his parents’ accident. His sense of responsibility (i.e., protective factor) mediated his risky behaviours (i.e., risk factor), and led him to make the healthy choices to positively impact his outcome. This supports Compas’ (2004) model explaining how the appraisal, stress, and coping process are equally important in understanding adolescent resilience.

**Parental ABI Changes the Family System**

The findings of the current study support previous research findings suggesting that an ABI results in changing the family (Carnes & Quinn, 2005; Charles, Butera-Prinzi, & Perlesz, 2004; Gan, et al., 2006; Orto & Power, 200; Webster, et al., 1999). Although it has been well documented that the individual ABI results in a domino effect, how this occurs has not been entirely understood. The current research suggests ways in which the larger family system is impacted as a result of the parental ABI. I will describe the themes that compose this category within the context of the research literature. These themes include (a) the view of the non-injured parent, (b) the view of the parent with the ABI, (c) changes in the family relationships, and (d) changes in family roles and responsibilities.

**The view of the non-injured parent.** The participants described perceiving their non-injured parent somewhat differently after their parent’s brain injury. This was because the non-injured parent needed to care for the other parent as well as the children. This included supporting the family financially as well as emotionally. Some participants perceived their non-injured parent doing the best they could given their resources, while
other participants viewed their non-injured parent as having their priorities misplaced. The participants acknowledged that most of the caregiving duties fell to the non-injured parent, but they all stated that they needed a parental figure to support them. The participants provided support to their siblings, their parent, and their non-injured parent, yet also felt that few were able to support them. This contributed to their sense of feeling alone in their experiences.

Although the research at this time does not describe this changed view of the non-injured parent, family systems-illness model (Rolland, 1994) can be used to explain it. Family systems theory states that changes within different parts of the system will inevitably impact other areas of that system (Kreppner & Lerner, 1989; Rolland, 1994; Schwab, Gray-Ice, & Prentice, 2000). The change in the injured parent results in a change in the non-injured parent. As a result, the child will perceive these changes in both their parents and will react accordingly. In this case, the participants changed their interactions with their parents as well as their demands upon their parents. This will be described in more depth in subsequent sections.

The view of the parent with the ABI. Similarly to the above discussion, the parent with an ABI experiences changes in their physical, cognitive, behavioural, psychological, and social functioning. When the participants witnessed these changes first hand, their parent’s ABI became more real and something to suddenly accommodate. The participants recognized the changes in their parent and started to acknowledge that their parent was different. This recognition of change followed by a sense of needing to accommodate those changes further supports the idea that the parental ABI acted as a trigger as described by Goodman et al. (2006).
In addition, this finding was consistent with the research literature indicating that family members first witnessed the changes and then acknowledged the differences in the injured family member (Arango-Lasprilla et al., 2008; Charles et al., 2007; Landau & Hissett, 2007). By simply acknowledging the changes in their parent resulting from an ABI, the family members started to make adjustments based on the parent’s abilities (Charles et al., 2007). This included the changes in their interactions with the parent.

**Changes in family relationships.** The participants described significant changes in their relationships with their parents, siblings, and extended family. The changes in the relationships with their parents were the result of their changed perception and interactions with their parent. As a function of these changed interactions, the relationship inevitably had to change to accommodate these differences. For many participants, the pre-injury relationship with their parents and siblings dictated the quality of the post-injury relationship. If their relationships were strong to begin with, they were strengthened by the adversity of a parental ABI, but if their relationships had some serious flaws (e.g., lack of trust, lack of past support, turbulent interactions, etc.), then their relationships were more likely weakened by the parental ABI. This is consistent with the family resilience framework described by Walsh (2003).

According to Walsh (2003), families that are considered to be resilient are believed to utilize their strengths under stressful conditions. However, families that have several weaknesses may have those weaknesses exacerbated under stress. Therefore, these weaknesses may become more apparent leading to increased risk for the disintegration of relationships within the family. While many of the participants came from resilient families as evidenced by their strengthened bonds with their family
members and increased resourcefulness under stressful conditions, other participants noticed more flaws within their family relationships because of the added stress of the ABI. It seemed that the parental ABI resulted in increased strain on existing flaws within the relationships, and in some cases, these relationships could not withstand the strain. The findings in the current research support the concept of family resilience.

Furthermore, the level of support that family members provided also strengthened or weakened the participants’ relationships with some family members. Some participants felt supported by their family members which contributed to their feelings of closeness with those family members. Other participants did not receive the support they had hoped for which was detrimental to the relationship. This finding is consistent with the research literature in that adolescents and emerging adults who feel supported by their social network which can include family members and friends feel closer to those individuals in their lives (Ciairano et al., 2007). This finding is also supported in brain injury research in that family and friends providing social support is a predictor of overall family system functioning after a brain injury (Gan et al., 2006; Webster et al., 1999). Changed relationships are another characteristic of the moving through and moving out phases of the integrated transition model (Goodman et al. 2006).

**Changes in family roles and responsibilities.** The participants described experiencing multiple changes in family roles and responsibilities. The participants acknowledged that the change in roles resulted from their parent being unable to perform their normal familial roles. For some participants, this meant that the parent was unable to cook, provide care, or maintain a household, while for others this meant that the parent could not work or contribute financially. To ensure that the family continued to function
and meet necessary societal demands, the roles and responsibilities of the parent were distributed amongst other family members. As a result, all the participants accepted new roles, routines, and responsibilities. This is a characteristic of the moving in phase of the integrated transition model (Goodman et al., 2006).

This finding is also consistent with the family systems-illness model in which Rolland (1994) explained that there is a role shift within the family that must occur due to the changes within the family system resulting from illness or disability. However, it is important to note that the parent’s role is not completely deconstructed and distributed to other family members because the parent can continue to actively portray some elements of their parental role, such as providing advice to the children (Rolland, 1999). Jason and Tammy’s mother, for example, continued to provide helpful advice while Jason and Tammy engaged in caregiving activities. Similarly, my mother also maintained her role by providing guidance in multiple life areas. In this way, our mothers were able to maintain their roles as parents while their children provided the necessary care that they could not perform. Rolland (1999) stated that this is a healthy approach as the parent needs to maintain their own sense of being a parent and the children need to know they still have their parent. This can also reduce the intensity of the ambiguous loss (Boss et al., 2007).

In some cases, the participants believed that they were responsible for replacing their parent’s role and responsibilities in the family. This is also consistent with Rolland’s (1994) family systems-illness model in that beliefs about family structure affected how these roles and responsibilities were distributed to the rest of the family. For example, Penny and Jason viewed themselves as needing to take their parent’s place
and responsibilities to ease the strain on the family and reduce the impact of the missing role in the family. However, as both Penny and Jason described, many of the responsibilities were eventually taken on by their siblings, their non-injured parent, and extended family because there were too many responsibilities for them to manage alone. Again, beliefs about family support became a critical component to overall family functioning because the family came together to share the responsibilities rather than place it upon one individual’s shoulders. This contributed to the family resilience as well as overall family system functioning because these families believed themselves to function as a team.

As the parent regained some abilities, the roles and responsibilities continued to shift as the parent attempted to take back their pre-injury role. Unfortunately, this resulted in the parent feeling particularly frustrated when their children were comfortable taking on a parenting role. Although most participants struggled with taking on caregiving or parenting roles in the family, participants also reported that they were happy to “give back” to their parent and finally support their parent for a change. As such, the participants’ parents needed to find a way to continue to be a “parent” in the family. For some, this meant becoming the disciplinarian while for others this meant providing advice and guidance on various topics. Again, this is consistent with Rolland’s (1994) model in that a parent needs to maintain some sense of their pre-injury role in the family to continue feeling like a parent. This approach is considered to be healthy and beneficial to the overall family functioning. The findings from the current study seem to support Rolland’s (1994; 1999) family systems-illness model, which explains multiple elements of the family systems change that occurs after a parental ABI.
Parental ABI and External Supportive Resources

Although family was the first line of defense for supporting the participants, the participants all reported seeking additional support from both informal and formal sources outside of their personal ways of coping. It is important to note that these supportive resources contributed to the perception of transitional experience of living with a parent with an ABI. I will discuss the following themes within the context of the research literature: (a) informal supports, and (b) formal supports.

Informal supports. Participants described relying upon their friends as well as the community for support to supplement the support or lack of support they received from their families. Participants who had received less support from their family relied more heavily on their friends. This finding is consistent with the research literature indicating that if parental or familial guidance is no longer available, adolescents and emerging adults will turn to their friends and same aged peers for support (Beyers & Goossens, 2008; Cavanagh, 2008). However, the difference between the current research finding and the research literature is that the participants who received sufficient support from their family also sought support from their friends and their community. For these participants, their perceived stress levels were considerably high within the family, and they reported needing a sanctuary outside of the family setting to manage their stress more effectively. This is consistent with other research suggesting that increased family stress results in adolescents seeking support and guidance from their same aged peers (Ciairano et al., 2007; Faber et al., 2003; Levitt et al., 2007).

Participants had both positive and negative experiences with their informal supports. Some participants found that some friends were understanding of their
experiences, willing to support them through their experiences, and helpful in their support. In addition, participants who sought support from their community found a sense of belonging and fellowship that allowed them to just be who they were without the stress of their parent’s ABI. These experiences are consistent with the research literature in that friendships and community involvement help offset the negative outcomes that could result from a parental ABI (Orto & Power, 2000), thus contributing to adolescent and emerging adult resilience (Compas, 2004; Masten et al., 2006). Furthermore, these experiences in external informal support also contributed to improving participants’ perceptions of the transitional experience of living with their parent with an ABI.

However, other participants felt that some of their friends at the time did not understand their experiences and were not supportive creating more stress in their lives than necessary. This finding is consistent with some of the research literature in that adolescents can experience changes in their social relationships as a result of various other life-changing events that are normal to adolescent development (Steinberg, 2000). As such, the experience of living with a parent with an ABI can add to this stress, as evidenced by the participants who had some negative experiences seeking support from their friends.

In addition, some participants also felt that the community was unhelpful as the community created a sense of stigma about the experience of living with their parent. This has also been found to be consistent with the research literature. Linden and Boylan (2010) found that the public viewed individuals with brain injuries as unhappy, aggressive, and dependent adults that can create problems when integrated within their communities. Although the participants may not have experienced this feedback directly,
they had experienced the effects of these misconceptions. For example, Tammy witnessed others pitying her and her mother in public because her mother was in a wheelchair. The pity of young caregivers is also consistent with the evidence presented by Aldridge (2008) in that the public perceives young caregivers as victims of unfortunate circumstances in which they are forced to care for their parent. These public views about brain injury and their caregivers impact the willingness of adolescents to access these informal supports because adolescents do not want to be stigmatized. These negative experiences with informal supports contributed to more challenges in the transitional experiences resulting from a parental ABI.

**Formal supports.** The participants accessed a variety of forms of formal support including doctors, rehabilitation specialists, counsellors and therapists, teachers, and school guidance counsellors. Doctors and rehabilitation specialists were usually accessed when the participants had questions about their parent’s injury or wanted to be included in their parent’s recovery process. Counsellors, teachers, and school guidance counsellors were typically accessed when the participants needed additional external support.

The formal supports that the participants accessed were both helpful and unhelpful in a variety of ways. Participants found that it was particularly helpful when they were provided with honest and fact-based information about their parents’ ABI as well as the expected recovery process. This eased some anxiety for some participants in that they were able to anticipate the changes. In some cases, being given the worse-case scenario was helpful because the participants were prepared for the worst and were usually pleasantly surprised when their parent positively exceeded their expectations.
This is unsurprising as Junque et al (1997) found that families require information about the ABI, the recovery, and how they can support the individual to promote well-being in all family members. The current research findings suggest that children need to be included in communications about their parent to help the child adjust to the changes occurring within the family, which is consistent with Rolland’s (1994; 1999) family systems-illness model. Those who did not receive information believed that information would have helped them cope.

Participants also found it helpful when adults in authority positions such as teachers and guidance counsellors were accessible and supportive. Some participants found that teachers who were informed of the parental ABI helped the adolescents by being available to talk when the participant needed. For example, Jessica described talking with her teacher about her experiences and felt comforted when her teacher said that everything will be okay. Her teacher’s attentiveness and words of encouragement validated her experiences and provided her hope that she would survive the experience. Similarly to these findings, research literature has shown that adolescents and emerging adults who are involved in their school community and also form relationships with their teachers are actively creating protective factors to reduce their risk (Rutter, 1994; Sasaki & Yamasaki, 2007).

Participants did not find formal supports helpful when the individual providing the support demonstrated a lack of understanding of the experience of living with a parent with an ABI. Unfortunately, this was the most common complaint about counsellors and therapists amongst the participants. Participants believed that counsellors and therapists demonstrated a lack of knowledge and competence in helping family members who have
lived with an individual with an ABI. Furthermore, the participants who accessed
counselling services were skeptical of the services, but were informed by adults or other
professionals that it would be helpful to them. Unfortunately, their negative experiences
with counsellors and therapists confirmed pre-existing negative beliefs about counsellors
and therapists. Therefore, these participants have indicated that they distrust or dislike
counsellors and would be unlikely to see one again in the future. This finding is new as
previous research has not investigated the proficiency and competence of counsellors in
supporting adolescents or emerging adults who were impacted by a family member’s
ABI.

Despite the research literature that provides descriptions of the common
experiences of families impacted by ABI along with counselling interventions (Charles et
al., 2007; Elbaum, 2007b; Kieffer-Kristensen et al., 2011; Landau & Hissett, 2008; Orto
& Power, 2000), there continues to be a lack of competence amongst counsellors and
therapists in this particular area. Research demonstrating the effectiveness of multiple
counselling approaches has found that interventions for families impacted by ABI have
been successful and beneficial (Charles et al., 2007; Dausch & Saliman, 2009; Elbaum,
2007b; Kreutzer, et al., 2009). These interventions were applied by practitioners who
were familiar with the area and were open to learning more about the experience from
those who had lived it. The participants indicated that most of the practitioners they had
encountered were either inappropriately focused for their needs (i.e., grief counsellors) or
had a clear agenda without listening to the participant’s needs in the session.

The participants agreed that there were few sources of appropriate and helpful
formal support available for adolescents and emerging adults living with a parent with an
ABI. Unfortunately, this is unsurprising based on previous academic literature disclosing the information and support needs of families impacted by an ABI that continue to go unmet (Charles, et al., 2007; Elbaum, 2007b; Florian & Katz, 1991; Junqué, et al., 1997; Orto & Power, 2000; Rolland, 1999). Finally, all the participants indicated that formal supports were necessary for adolescents living with their parent because many adolescents and emerging adults may not have been as resilient as the participants. This suggestion is consistent with other research studies discussing the needs of families impacted by an ABI (Junque et al., 1997; Kreutzer et al., 2009; Orto & Power, 2000; Rolland, 1999).

Furthermore, many participants suggested it would have been helpful to know others who had experienced the same phenomenon within their same age group and to be provided with the opportunity to meet with them in a setting such as a support group. This was primarily so that the adolescents and emerging adults could continue to be adolescents and emerging adults but have a space where they could receive support outside of their family members. The participants believed that a support group would reduce the isolation of the experience and the sense of being the only older child living with a parent with an ABI. Interestingly, this was the most highly recommended form of support amongst the participants. This recommendation has not been found in the literature as this area of research is still relatively new.

**Personal Coping with Parental ABI**

In an effort to manage their stress, participants described various ways of coping that helped them alleviate the immense amount of stress resulting from the parental ABI. The themes that composed this category were strategies that most of the participants used
at some point during their experience living with their parent. Each strategy used contributed to the resilience of the individual as he or she navigated this transitional experience. I will discuss the themes within the context of the research literature. These themes include (a) tackling the problems, (b) tackling the emotions, (c) avoidance and distraction, (d) compartmentalizing stressors, (e) maintaining a sense of normalcy, and (f) optimism and hope.

**Tackling the problems.** Some participants used strategies that helped them tackle the source of the stress. These participants made an effort to better understand their experiences with their parent, eliminate uncertainty, and anticipate what could happen as a result of a parental ABI. This was in response to the uncertainty felt throughout the experience of this phenomenon as well as being unheard and ignored in the process of rehabilitation. This finding is consistent with Lazarus and Folkman’s (1984) theory of stress appraisal and coping in that the participants developed strategies based on their appraisals of their personal resources to cope with the stressful event. A lack of information was believed to be the source of the stress, and thus, participants executed problem-focused coping strategies to eliminate this source of stress. However, this seemed to be the only area that participants believed to be within their control to change as gathering and seeking information was the only problem the participants could tackle. Most of the participants found that this particular strategy was unhelpful as they were unable to get the information that they needed at the time to eliminate the stressor.

**Tackling the emotions.** All the participants described engaging in strategies to effectively manage their emotional experiences resulting from the stressor. This involved using social support to vent their frustrations, sadness, anger, and happiness. When
social support was insufficient in managing the emotional experiences, participants used various outlets to help them express their emotions in a safe way. For many this outlet involved engaging in creative projects. Many participants indicated feeling helpless in terms of their parent’s condition and found that this kind of emotional release was helpful. This finding supports Lazarus and Folkman’s (1984) theory of stress appraisal and coping in that the participants used a form of emotion-focused coping to help them manage their emotional experience when the problem itself could not be managed or eliminated. This kind of coping was helpful for the participants because the problem creating the stress was perceived to be outside of the participants’ control which is also consistent with Lazarus and Folkman’s theory of stress and coping.

Avoidance and distraction. The participants described relying on distraction and avoidance techniques due to a sense of helplessness in regards to the stressor. In this case, the participants found distraction and avoidance to be helpful at times, especially when the participants needed to distance themselves from the problem. Avoidance and distraction strategies were typically used during the initial phases of the transitional experience due to the shock of learning the experience as well as the uncertainty of their parent’s condition. As a result, the participants engaged in other activities such as becoming involved in extra-curricular activities, gaining intense focus on their school work and activities, staying outside of the family home, and continually focusing on others’ problems. The participants found these strategies to be helpful because they allowed them the time and space to deal with their problems at their own pace and reduce the possibility of becoming overwhelmed by the number of problems and stressors. These findings about avoidance and distraction are contrary to the position put forward
by Lazarus and Folkman (1984), who indicated that avoidance and distraction strategies are generally unhelpful.

However, the findings are consistent with Flach’s (1988) views in which strategies that would typically be viewed as unhelpful and distracting from the problem can also be a contributor to the individual’s resilience. All the participants distanced themselves from their problems by engaging in other activities that required their attention such as their education, physical activities, community involvement, or creative projects. These activities provided enough distance for the participants to manage their circumstances at home and decrease the impact of the stressful life event. This is consistent with Flach’s conceptualization of resilience and coping in that individuals confronted with problems that cannot be “resolved” in the traditional sense requires creative problem solving. Therefore, distancing can be used to develop new and creative ways of resolving the challenge or coping with the stressor. As such, this pattern of distancing which may appear to be distraction or avoidance coping techniques is actually helpful to the individual living with his or her parent and contributes to their overall resilience (Flach, 1988).

**Compartmentalizing stressors.** The participants used other personal ways of coping that helped them manage how and when they coped with a particular stressor. These strategies would be considered protective factors as it helped the participants manage their stress (Compas, 2004; Flach, 1988; Rutter, 1992). In this case, compartmentalizing stressors was an effective stress management system that combined distancing and coping strategies to process the problems and the emotions. The participants described periods of coping with the stressors one by one, then distancing
themselves from their stressors to focus on other life areas. This description is consistent with the dual process model of coping (DPM; Stroebe & Schut, 1999). Although this model is typically applied to coping with grief and loss, it also seems appropriate for adolescents and emerging adults who are coping with the changes and losses resulting from their parent’s injury.

The DPM states that individuals need to oscillate between loss-oriented (i.e., associated with the primary loss) coping and restoration-oriented (i.e., associated with secondary stressors) coping to successfully adjust (Stroebe & Schut, 1999). This model combines the grief and mourning processes with the need to continue moving forward in life. Loss-oriented coping can include crying and sharing memories about the person who was lost. Restoration-oriented coping can include changing roles within the family to compensate for the loss or activities that help the individual to restore a normal life without the individual (Boss et al., 2010). Stroebe and Schut (1999) believe that by balancing between both loss-oriented and restoration-oriented coping, individuals will be able to continue to acknowledge their grief and their loss while continuing to move forward and reconstruct meaning for the loss they have experienced.

Interestingly, the DPM has not been applied to individuals coping with ambiguous loss, let alone adolescents and emerging adults coping with ambiguous loss. However, based on the current study’s findings, it seems that it would be an appropriate framework to better understand the successful coping strategies of the participants as they built their “new normal” in their everyday life. Given the support for the DPM, this study could also support the use of the DPM in counselling practice for this particular group of individuals as recommended by Servati-Seib and Taub (2010). This model can be helpful
in guiding the unique grieving process of the children of parents with ABIs and in acknowledging the ambiguous loss while simultaneously restoring a normal life (Boss et al., 2011; Stroebe & Schut, 1999).

**Maintaining a sense of normalcy.** Maintaining a normal life area is another strategy used to help the participants manage cope with their stressors at their own pace. Participants described making multiple attempts at maintaining a life area that they considered to be normal. For some, this normal life area was school or work; for others, it was a hobby; and for still others, it was a community activity. Some participants described this life area as a sanctuary to help them gain distance from their problems. Other participants described this life area as an area they needed to improve to ensure that one life area is stable and safe. This coping strategy was useful to the participants because it gave them a life line – something stable to hold onto in the event of a crisis and something to use to help them distance themselves from the stress at home.

Maintaining a sense of normalcy can contribute to the DPM outlined by Stroebe and Schut (1999) in that it can allow the adolescents and emerging adults to create distance and contribute to a regularly functioning life. However, this coping strategy also provides a sense of stability in a time of chaos and uncertainty which is a characteristic not supported by the research literature. In this way, this coping strategy is unique to this study as it has not been discussed in previous research studies.

**Optimism and hope.** Optimism and hope was a strategy participants used to cope with their circumstances in that they were able to change their attitudes about their experiences. The participants learned to become optimistic to foster their hope in their parent’s recovery and their hope that their lives would continue to improve. Although
optimism has not necessarily been associated with coping with a family member’s ABI, it has been found to contribute to individual resilience (Baldwin et al., 1990; Rutter, 1994; Compas, 2004).

It seems that hope also contributed to the resilience of the participants as hope encouraged them to continue supporting their parent. It was because of hope for an improved relationship and the parent’s recovery that many participants did not give up on their parent and continued to encourage him or her throughout the recovery process. It has been speculated in the research literature that it is because of the hope from the families that family support for individuals with ABIs is the most effective type of support during the recovery process (Doidge, 2007; Kreutzer et al., 2009). This speculation has yet to be confirmed in a research study, yet hope is becoming a new interest in the field of disability counselling.

**Limitations**

There are several limitations that impact the interpretation of the findings in the current study. First, it is important to note that the current research findings are based on individuals from a variety of backgrounds and family structures including single parent homes, two-parent homes, and blended families. My observations and conclusions were based on these variable contexts, meaning that I may have missed elements that are unique to specific family structures such as traditional two-parent homes or single parent homes. These structures may add complexity to the experience of this phenomenon and the general essence of the experience may be too simple for some families. However, the diversity of my sample was also a strength of this research because the findings from this study can be used to tentatively inform the general experience of families impacted by
parental ABI with various structures and backgrounds. Further research is required to provide support for these exploratory findings and capture the unique differences inherent in certain family structures.

Second, another limitation was that no information on socio-economic status (SES), parental education level, or professional status was collected. Consequently, it is impossible to comment on any qualitative differences between the experiences of adolescents from various SES, parental education, or professional status levels in this study. In future studies, it may be worthwhile to explore the link between SES of the families and the experience of the adolescents since the loss of financial resources seemed to be such an important issue in the current study.

Third, the findings are limited to ethnically Canadian families with influences from other cultures (i.e., Chinese, Greek, and Lebanese). Although cultural influences seemed to be present in the current study, I could not determine qualitative differences in adolescent experiences based on the sample of participants. It would be useful to explore how culture may impact the phenomenon to better understand the potential influences that can affect the nature of the experience.

Similarly, it is unclear how other diversity factors (i.e., lesbian, gay, bisexual, or transgender/sexual [LGBT] identity) could impact the experience of adolescents while living with his or her parent. As LGBT identity could evolve while the adolescent is exploring his or her general identity, a parental ABI might create additional difficulties for the adolescent transitioning into adulthood. This is supported by Tyson’s experience as he was recognizing his sexual orientation at the same time as he was coping with his stepfather’s ABI.
Fourth, the majority of the participants indicated that their parent had acquired their brain injury when they were between the ages of 14 and 18 years. One participant experienced the phenomenon at a younger age of 12 years. In this case, Rebecca’s experience was unique as she was more frequently separated from her family, which resulted in less family communication and information about her stepfather. However, out of all of the participants, she was also the only one who participated in her stepfather’s rehabilitation efforts. This might be attributed to any number of factors, but it is possible that she was more frequently placed under her stepfather’s care when her mother was not able to be present. There appear to be slight differences in the nature of Rebecca’s experience as a younger adolescent, but it is unclear how various factors (e.g., age, separation from the family, individual resilience) may have contributed to this. That being said, the findings can likely be used to inform the experience of younger adolescents, yet more research is required to better understand their unique challenges in their experiences.

Fifth, the participants in this study were volunteers who were willing to talk about their experiences. All of them came from intact families and reported having successfully adapted to their parent’s ABI. Despite my efforts to recruit individuals from various backgrounds, it seemed that only those who arrived at a positive view of their experiences chose to participate. One might wonder about the experiences of those who did not choose to volunteer or who had not arrived at a positive view of their experiences.

Sixth, I also wonder about the individuals whose families disintegrated as a result of the parental ABI. Unfortunately, these individuals are less likely to participate because of their need to simply walk away from their past and not revisit negative or
painful memories. Many may view this reaction as an “unsuccessful transition”, yet it is important to note that some adolescents may only be able to survive if they walk away from the situation and engage in self-preservation techniques to help them move forward into adulthood.

Finally, it is important to note that consistent with a heuristic inquiry, I, the researcher, was an insider to this experience. As an insider, I needed to ensure that I found balance between my personal biases about the experience and the participants’ views and understanding of their experiences. In this process, it is expected that the researcher and the participants create a shared meaning that leads to the results. In an effort to maintain this balance, I engaged in several self-dialogues as well as consulted with my supervisor to help me recognize when my biases overly influenced the shared meaning developed during the interview and analysis processes. Despite my efforts to maintain the quality of the data, it is possible that my biases may have had more of an influence on the shared meaning than intended or expected. At the same time, it is also possible that my insider experience helped me develop more insight into the experience and guide my research process. Because I was transparent about my insider experience, the participants were more willing to speak honestly about their experiences, which led to richer data. In addition, the participants appreciated talking to someone with experience of the phenomenon because they knew I would understand and not judge them. As the participants described, this contributed to their willingness to participate in the study.

**Implications for Theory**

There are a number of implications for theory that arise from the findings of the current study. The implications for theory encompass the following theoretical areas: (a)
transition models, (b) family systems theory, (c) grief and loss theories, and (d) coping, stress and resilience. The implications in these theoretical areas will be discussed in the following sections based on the findings of the current research as well as the relevant literature.

**Transition Models**

The existing transition models for adolescents and emerging adults experiencing unusual life events do not sufficiently match the experiences shared by the participants. Most of the transition models discussed in the literature (i.e., Arnett, 2006; Erikson, 1968) focus on developmental concerns, but few transition theories combine adolescent and emerging adult development with event- or non-event based transitions. Despite this, the integrated transition model (Goodman et al., 2006) was the best fit for the phenomenon given the existing models available and has been shown to be applicable to adolescents and emerging adults. However, there seems to be a clear need for an event-related transition model that also considers adolescent and emerging adult development. Such an intersectional model would be a better fit for this phenomenon and would help us better understand how adolescent and emerging adult development theory informing identity formation, peer influences, parental authority, and attachment, can influence the experience of a transitional event.

**Family Systems Theory**

As expected, the current research informs and supports family systems theory across the developmental lifespan as described by Kreppner and Lerner (1989) and Rolland (1994). It seems that few newer studies exist investigating the value of the developmental family systems theory, which raises several questions. If it is believed
within the literature that a developmental family systems theory is no longer applicable to long-term family function, what has replaced it? There seems to be few other alternatives to explain the long-term development and adaptations that families need to make in response to individual system development and changes. The current research supports the idea that family members must constantly adjust to meet the continuous demands placed upon them as individual family members grow, change, and develop (Kreppner & Lerner, 1989).

However, because the current research is atypical to normal family development, Rolland’s (1994) family systems-illness model, which is based on the developmental family systems theory (Kreppner & Lerner, 1989), is the best fit with the familial experiences described by the participants. Rolland (1999) suggested that rather than conceiving of the parent’s injury or illness as a single event that must be managed, the family must constantly adjust and adapt as the individual’s condition changes. This may explain why children from these families exhibit considerable adaptability in their emerging adult and adult lives. They must constantly be prepared to adapt to changes in their family member’s condition, and this skill is carried over into other life areas. Interestingly, little research exists supporting Rolland’s (1994) model despite the wealth of information about families dealing with acquired disabilities and illnesses.

Although it seems that this particular branch of theory is relatively new, it is clear that it is the most accurate in describing the experiences of adolescent children living with their parent. However, it would be worthwhile to consider enhancing the research to provide support or counter this model to determine its applicability to multiple types of disabilities and illness as well as various family structures and dynamics.
Grief and Loss Theories

The findings in this study provided evidence to support the ambiguous loss theory outlined by Boss (2007; 2011). In addition, the findings also supported the use of the DPM to understand how adolescents cope with the ambiguous psychological loss of their parent with the ABI. However, these two theories have yet to be combined and explored. Based on the current study’s findings, it seems that it would be an appropriate framework to better understand the successful coping strategies of adolescent and emerging adult children living with a parent with an ABI as they build their “new normal” in their everyday lives. Given the support for the DPM, this model can be helpful in guiding the unique grieving process of the children of parents with ABIs and in acknowledging the ambiguous loss while simultaneously restoring a normal life (Boss et al., 2011; Servati-Seib and Taub, 2010; Stroebe & Schut, 1999). Because ambiguous loss is believed to be a complicated grieving process, it would be beneficial to outline how the DPM could be used intentionally to aid counselling psychologists as they work with adolescents coping with ambiguous loss.

Resilience, Stress, and Coping

The findings support the concept of resilience as a life-long concept that is constantly evolving and changing as the individual encounters new stressful and adverse situations (Flach, 1988; Masten, et al., 2006; Rutter, 1992). The participants in this study demonstrated considerable resilience to these challenges and were able to share their overall appreciation for the benefit that it has served them in their emerging and full-fledged adulthood. The participants attributed their resilience and coping strategies in emerging adulthood and adulthood to their experiences living with their parent with an
ABI. This suggests that resilience learned in childhood, adolescence, and emerging adulthood is carried into later life.

The current study suggests that resilience needs to be considered when conceptualizing the experience of children of any age living with a parent with an ABI as it seems that protective and risk factors will heavily influence how they cope with the experience. Resilience would also inform the coping strategies used in adulthood when these individuals encounter challenges, thus informing their adjustment as adults. It would also be useful to consider family resilience (Walsh, 2003) to inform the coping strategies of family members impacted by parental ABI.

It is also important to note the difference between the distancing as described by Flach (1988) and avoidance coping strategies as described by Lazarus and Folkman (1984) as it influences resiliency in the face of adversity. Flach indicated that distancing is helpful for the individual to gain insight into the problem. The individual must be prepared to return back to the problem to deal with it. Fortunately, this is how most of the participants used avoidance and distraction techniques. However, it may be beneficial to clarify what makes a “helpful” or “unhelpful” distraction for practitioners to better support a natural coping process that allows for the oscillation of distancing from problems and coping with stressors as per the DPM (Stroebe & Schut, 1999).

**Implications for Research**

As an exploratory study, the current research provides a wealth of information to inform future research endeavours. First, it would be beneficial to investigate how the resiliency of adolescent children, emerging adults, and families impacted by parental ABI can be intentionally strengthened to reduce the occurrence of negative outcomes. Future
research would be helpful in providing concrete ways that adolescents, emerging adults, and their families can enhance their resilience while coping with a parental ABI.

Second, future research may need to consider the conceptualization of parental ABI as a transitional event within the family. By testing this hypothesis, we may be able to better understand the transitional and developmental process that both the family and family members experience as a result of a parental ABI. This information would also be helpful in developing a better transitional model for the adolescent and emerging adult children involved better address their experience of a parental ABI coupled with their developmental process. An accurate transition model for children and adolescents impacted by an ABI could help families and professionals anticipate their experiences.

Third, it would be interesting to consider the experiences of children of all ages who come from specific types of families such as two-parent, blended, or single parent families in which a parent has acquired a brain injury. This would help clarify the findings of the current research while also identifying unique characteristics in specific types of families that could impact the overall family resilience and family functioning. Furthermore, it could aid us in understanding the experience of adolescents who may already be in a vulnerable position within their family.

Fourth, it would be interesting to determine the impact of specific ethnic or cultural backgrounds on how the adolescent manages and copes with the transitional experience. This information would be pertinent as individuals from different cultures may have different beliefs about disability, family support, and family roles. In addition, individuals from different cultures may also have different sources of resilience that may impact the overall experience of a parental ABI. Similarly, the impact of other diversities
such as adolescents and emerging adults who are exploring a LGBT identity may encounter different challenges and different sources of strength.

Fifth, it would be beneficial to research the effectiveness and practical use of the family systems-illness model (Rolland, 1994) with families impacted by ABI (parental or otherwise). It seems there is little support in the use of this model for families managing an ABI. The findings from the current research suggest that this model would have tremendous applicability in conceptualizing parental ABI, yet there seem to be few studies examining the application of this model. Therefore, it would be beneficial to develop research to test the usefulness of this model in understanding the experience of families impacted by ABI.

Sixth, because the academic literature suggests the possibility of vicarious traumatization amongst children who have lived with a parent with an ABI, it would also be valuable to better understand how counselling psychologists can offer support in this unique type of concern. Given that vicarious traumatization in children of parents with acquired disabilities is a relatively new research area, it is unclear how children may experience this trauma. Although the current research study did not directly suggest the presence of trauma as a result of a parental ABI, it is still important to consider the possibility of vicarious traumatization as a concern amongst family members. Further research in this area is needed.

Finally, it is necessary for future researchers to disseminate their knowledge to professionals working in the field including practitioners, stakeholders, and policymakers who may not have the time to read or the access to academic journals. It is clear in the research literature that there is a need for appropriate service provision, yet this
information continues to not reach the individuals who need this information the most. Therefore, it is imperative that new developments, such as those shared in the current research study, are shared in plain English amongst family members, caregivers, survivors, support staff, professionals, medical staff, rehabilitation staff, funders, and other stakeholders to allow the practitioners in the field to better support those in need.

**Implications for Practice**

The implications for practice are numerous because of the exploratory nature of this study. Many of the recommendations came from the participants coupled with my personal experiences. Despite all the research literature suggesting the need for formal supports, there continues to be gap in service provision and practice (Junque et al., 1997; Kreutzer et al., 2009; Orto & Power, 2000). The participants also indicated that there was a clear need for formal supports for individuals living with a parent with an ABI. Because there are multiple professionals who may be encountering the adolescent and emerging adult children, it is important to note that professionals will need to work together to ensure that the needs of the adolescent, family members, and the parent have been met.

Given the changing nature of health and wellness care as it moves towards interprofessional collaboration (WHO, 2010), it would follow that counselling psychologists need to be educated about how health, illness, and disability can impact the family members and their development. This could take place as an additional training session or perhaps a simple document sharing key information about the experiences of family members after a parental ABI, acquired disability, or illness. This may improve the existing competence of therapists and thus, improve the quality of care for
adolescents and emerging adults living with their parent by becoming more familiar with the phenomenon.

Based on the findings and past research literature (Carnes, 2005; Elbaum, 2007a; Junque, et al., 1997; Rolland, 1999), counselling psychologists need to be willing to work with other professionals as they support families impacted by a parental ABI. This may require counselling psychologists to advocate for the children to be included in the process of rehabilitation and therapy. The current research demonstrates that excluding or ignoring family members from a familial event such as a parental ABI is not helpful to the adolescent and emerging adult children as it excludes them from natural family processes of developing a shared meaning of the event within the family. By creating a shared meaning of the event, the family can improve their resilience and become a source of strength for the children rather than a risk factor (Compas, 2004; Rolland, 1999; Walsh, 2003).

Therefore, it is recommended that counselling psychologists clearly communicate with the family and seek collaboration with medical and rehabilitation specialists in an effort to better support the family as well as the adolescent children. Children especially need clear communication about what is happening in their family as well as how they may proceed. The process of delivering the appropriate information may need to be refined for younger children as their comprehension of the issues may be limited, but I must stress that the parents or adults within the family communicate with their children about this event and the expectations. This can ease the anxiety for all family members involved allowing them to cope with the life-changing event as well as alleviate unnecessary uncertainty within the family.
Furthermore, counselling psychologists need to be sensitive to the needs of the family members in how they provide information and resources as well as the information itself. This includes directing the family towards other supportive resources, providing accurate information, and doing so with sensitivity. Most of the participants indicated that they were not informed of what to expect from their parent’s injury or even what the injury entailed. If the adolescent and emerging adult children have accessed support from the counselling psychologist, it is imperative that the counselling psychologist support individuals in their effort to understand what is happening within their families. In some instances, this may mean advocating for the adolescent or emerging adult to ensure that information is clearly presented to him or her by a medical professional or rehabilitation specialist.

Rehabilitation professionals provided considerable support for the participants whose parents accessed services to aid their recovery. The rehabilitation professionals were able to provide more applicable information in plain English, yet few were qualified to support the children in the parent’s recovery as that was not part of their job or their training. However, allowing the family members, especially the children, to be involved in the rehabilitation process gave them the opportunity to better understand the parent’s challenges and strengths. It also allowed the family members to build the relationship with their parent while also helping their parent with the exercises in the home environment.

The participants agreed that additional support outside the family would have been helpful. Those who accessed professional therapeutic supports found it unhelpful in that they believed it did not meet their needs or they felt their therapist did not listen to or
understand them. This is interesting because the purpose of therapy is to address the needs of the client. This suggests that there is a potential gap in therapist competence in helping adolescents, emerging adults, or other family members impacted by a parental ABI. Therefore, counselling psychologists need to be aware of the phenomenon to provide ongoing support, but they do not need to be specialists in the area. I believe that if the counselling psychologists were more familiar with parental ABI and the implications surrounding the phenomenon that their skills in supporting these individuals would improve. Counselling psychologists, however, would need to be honest in regards to their comfort level in supporting individuals with ABI and their families.

Counselling psychologists need to reassure their young clients in that clients are the experts on their own experiences, and the psychologist is there to provide support, skills, and tools to help youth manage their experiences. It would be integral to have a frank and honest conversation with youth at the beginning of the therapeutic relationship about being unaware of these experiences. This would allow the adolescents to share their fears and concerns at the beginning of the therapeutic relationship. It would also help the adolescents decide if they would like more specialized supports based on their needs, thus also empowering them to take control over their own care.

Counselling psychologists need to be cognisant of the complexity of this experience and how closely linked the child is to their parent’s recovery process. The current findings indicate that as parents recover, adolescents are also able to “recover” and continue on with their lives. However, if the parent suddenly relapses in symptomology, this added stress creates more problems for the adolescent. Counselling
psychologists need to be aware of the fluctuation in ABI to better support the adolescent throughout the recovery process.

In addition to therapeutic intervention, support groups for these youth seem to be critical as all the participants stated that if there was a support group with other teens and emerging adults impacted by a parental ABI, they would be more than willing to participate in it. This was in part because all of them found it helpful to talk to other people who have had similar experiences. Above all else, this seems to be the most important supportive service recommended by this particular population.

Conclusion

Adolescence and emerging adulthood are critical phases in human development during which individuals explore their identity, build relationships, and begin to explore what it could be like to be an adult. During these formative years adolescents and emerging adults are vulnerable, but not because of the storm and stress hypothesis. They are vulnerable during these years because this is the stage of life during which adolescents and emerging adults develop a sense of self in relation to their world and develop critical tools to take into adulthood that could make the difference between a resilient and an at-risk adult. Family trauma, stress, or crises can disrupt the normal developmental progress of adolescents and emerging adults and test their resilience as they attempt to cope with their experiences.

A parental ABI can be detrimental to the wellbeing of adolescents and emerging adults, but it can also be an experience that changes the individuals for the better. This is because of the numerous changes that occur and continue to occur after a parent acquires a brain injury. As the current study shows, changes in the parents result in changes in the
relationships, which also result in changes in the family system. Therefore, the adolescents and emerging adults impacted by parental ABI must quickly adapt to the changes in their family system, their relationships, their familial roles and responsibilities, and their sense of self as an adolescent or emerging adult. They must reconstruct their world view, their family view, and their sense of self to accommodate the impact of a parental ABI. This world view is highly dependent on support from external resources, individual resilience, and the individual’s ability to use helpful coping strategies. The complexity of the changes and the development of a “new normal” provide evidence that a parental ABI is a transitional experience for adolescent and emerging adult children.

It is important to note that not all adolescents and emerging adults will respond positively and be able to reconstruct positive meaning in their experiences. However, by fostering the resilience of the children impacted by parental ABI, supporting their normal developmental process, acknowledging their grief, encouraging their involvement with the family throughout the rehabilitation process, and validating their experiences, counselling psychologists can make this transition easier. Although the participants and I did not receive a lot of support during our experiences, we presented our stories to help others understand the magnitude and complexity of the experience. I share their hope that other adolescents and emerging adults do not experience the same unnecessary struggles we have. By sharing our experiences, we hope that you will make a difference in the lives of adolescents and emerging adults living with a parent with an ABI.
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Appendix A: Interview Questions

Demographics

1. Current Age:
2. Sex:
3. Age at the time of the parent’s ABI:
4. Education level:
5. Current age of the parent with ABI:
6. Sex of parent with the ABI:
7. Age of the parent at the time of the ABI:
8. Diagnosis of Injury (was ABI diagnosed? Severity?):
9. Cause of Injury (illness, medical complication, trauma?):

Interview Questions

Main Question: Tell me about what it was like for you growing up living with a parent with an ABI? You might begin by focussing on what was it like for you before your parent incurred the ABI and then what it was like for you after your parent incurred the ABI.

Follow-Up Questions

1. What was it like living with your parent before his/her ABI?
   a. How was your relationship with your parent before the injury? What was it like? How close were you to your parent?
   b. What were your family dynamics before your parent’s injury (family roles, relationships, etc)?
2. What was your experience living with your parent immediately after the ABI?
a. What changed in comparison to before the injury? How did it change?
b. How did you feel? Cope?
c. What support did you have during this time?
d. If I were to meet your family in the midst of this, what would I see?

3. How did you adjust to your parent’s ABI? What was it like for you to adjust to your parent’s ABI?
   a. What did you find helpful in this adjustment process?
   b. What do you think would have been helpful?

4. How has this experience shaped you as a person/ adult?
   a. What does your life look like now?
   b. How has this shaped your family?
   c. Looking back on this experience now, what has helped you grow into adulthood?

5. What words of advice would you give a person who is going through living with a parent’s adjustment to ABI right now?

6. What else would you like to tell me about your experience that we haven’t already discussed?
Appendix B: Recruitment Documents

Recruitment Script

I am a graduate student doing my MSc. in Counselling Psychology with the University of Calgary. Because my program is based on a scientist-practitioner model, part of the requirements is to complete a research project and thesis to later defend. I have chosen a topic that I am quite passionate about, but I need your help to recruit my participants.

I am going to look at the experience of adolescent and young adult children living with a parent with an acquired brain injury. However, I intend to talk to the children as adults who have made it through their transitional phase of adolescents to gain their retrospective account of what it was like for them to live with their parent. My goals for this research is: (1) to raise awareness of the adolescent experience in these circumstances to improve rehabilitation and counselling practice to ensure families are involved; (2) to help these individuals share their story that has likely been unheard and ignored; and (3) to improve their personal healing process simply by being open and willing to share the unfiltered version of this story. I know many of these things to be the case primarily because I was in their shoes once. It is for this reason that I would like to give these individuals a chance to share their experience with me – to make it known amongst the community, and to help them heal.

I am contacting you as an agency working with people with ABI because of the hidden nature of this group. I request that you pass along information about the project as well as my contact information if the individual would like to participate. If you have other options to help my recruitment process, I am open to hearing them and acting on
them. I would appreciate any help you are willing to offer for this research project. You are welcome to contact me at (403) 461-2769 or by e-mail at efreema@ucalgary.ca.
Information Sheet

This study is aimed at raising awareness about the experience of adolescents and emerging adults growing up living with a parent with an acquired brain injury (ABI). Families are often left out of the equation when trying to help a person with an ABI, despite some of the research stating that including the family in rehabilitation and counselling can help the healing process for all involved. Although academics and professionals know a fair amount about the effects on spouses, siblings, and parents, very little is known about the impact on the adolescent children of individuals with ABI. The principal researcher, Aiofe Freeman, understands some of the struggles families experience as she lived with a parent with an ABI in her own adolescence and understands the area of need. Research tends to inform practice; therefore, by exploring the experience of adolescent children growing up living with parents with ABI, we can start addressing the potential concerns that are unique and may be troublesome for this group of individuals. To participate in this study, you need to fit the following criteria:

- Currently, be an adult aged 18 to 30
- Your parent had an ABI – an injury to the head that occurred after birth resulting from a medical (e.g., removal of tumour), trauma (e.g., struck by or against objects), or illness (e.g., encephalitis, stroke, etc).
- At the time of your parent’s ABI, you were between the ages 13 to 21 years

As part of your participation, you will be asked to engage in the following activities:

- A single 1 to 2 hour interview to talk about your experience of growing up living with a parent with an ABI.
• A review of a summary of the interview over a 2-week period to ensure that this information was accurate and representative of your experience – this is also your opportunity to add information that may have been missed or not discussed.
  
  o This will also include a meeting or telephone conversation to discuss the changes or additions to make the summary more complete.

If you are interested in participating or would like more information, please contact Aiofe Freeman. You are under no obligation to participate if you decide to contact Aiofe and remember that the choice to participate is entirely yours. The contact information is as follows:

  **E. Aiofe Freeman, M.Sc. Candidate**

  **Phone: 403-461-2769**

  **E-mail: efreema@ucalgary.ca**

  Supervised by Dr. Sharon E. Robertson, R. Psych

  **Phone: 403-220-6542 (contact only if you have concerns about the study**
Does your parent have a brain injury that happened when you were a teenager?

Are you an adult now?

Researchers at the University of Calgary want to know about your experience as a teenager growing up living with your parent before and after their acquired brain injury (ABI). Share your story with the researchers! With more research in this area, it opens so many doors to aiding the family members of people with brain injuries.

☑ Are you between the ages of 18 and 30?

☑ Did your parent have a brain injury when you were between the ages of 13 and 17?

☑ Do you want to share your story?

Then contact Aiofe Freeman at (403) 461-2769 or e-mail at efreema@ucalgary.ca for more information about this innovative study. Participate and you can earn $20!
Appendix C: Consent Form
Name of Researcher, Faculty, Department, Telephone & Email:

E. Aiofe Freeman, MSc. Candidate, Faculty of Education – Educational Studies in Counselling Psychology, Phone: (403) 461-2769, e-mail: efreema@ucalgary.ca

Sharon E. Robertson, Ph.D., Professor, Faculty of Education – Educational Studies in Counselling Psychology, Phone: (403) 220-6542, e-mail: sroberts@ucalgary.ca

Supervisor:

Sharon E. Robertson, Ph.D., Professor, Faculty of Education – Educational Studies in Counselling Psychology, Phone: (403) 220-6542, e-mail: sroberts@ucalgary.ca

Title of Project: The Experience of Adolescents and Emerging Adults Living with a Parent with an Acquired Brain Injury: A Retrospective Study.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details 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.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study.

Purpose of the Study:

The purpose of the study is to learn more about the experience of an adolescent or emerging adult growing up living with a parent with an acquired brain injury (ABI). This type of brain injury is incurred after birth and can be caused by a medical issue (e.g., stroke), trauma (e.g., struck by or against objects), or illness (e.g., encephalitis). Because ABI can result in changes in the parent, this event may also change the family dynamics. However, the experience of the children of individuals with ABI is largely ignored in the research literature. Therefore, the goals of this research are not only to learn more about their experience, but also to give a voice to the children of individuals with ABI.

You were invited as a participant because your experience and story of living with a parent with an ABI as an adolescent is valuable. Although you are an adult now, you can use your hindsight to offer insight and new interpretations of your thoughts, feelings, and behaviours of the past to help the researcher understand what it was like for you and how you were able to manage these changes to your family dynamics as an adolescent.

What Will I Be Asked To Do?

As a participant in this study, you will be asked to engage in a 1 to 2 hour semi-structured, audio-taped, in-depth interview. In this interview, the researcher will ask you several questions about your and your parent’s demographics, your family’s dynamics prior to and after your parent’s injury, and your personal experience of living with a parent with an ABI. This will include questions about your thoughts, feelings, behaviours, and the coping strategies that you used...
before and throughout your parent’s recovery process. Online interviews can be conducted using the same format as the face to face interview; however, the researcher will record the informed consent process online and ask you to clearly state your name for the recording. Online interviews will only be conducted provided that you are unable to meet with the researcher face to face.

This interview will be later transcribed and converted into something called an individual depiction. This individual depiction is a representation of your story as the researcher understood it, and it is aimed to reflect the meanings associated with your experience. To ensure that I have accurately captured your experience, the individual depiction will be given back to you by e-mail in PDF format within 6 months of the interview date for you to review. You will have a two week period in which you will be requested to read over the summary and provide feedback, corrections, and edits to ensure the accuracy to your experience. This feedback can be given back to the researcher by scheduling a time to have a phone conversation or a second interview to ensure that there is no miscommunication and provide better understanding. If you do not respond to the request for feedback on the individual depiction, the researcher will assume that the participant approves of the individual depiction as it is.

Your participation is entirely voluntary and there is no obligation to participate. You may withdraw from the study at any time at no cost or loss of benefits to which you are entitled. Your participation or lack thereof will not impact or affect the services you are receiving from various agencies. Furthermore, you will still receive the $20 honourarium despite withdrawal from the study. However, any data collected to the point of withdrawal may still be used for research purposes. If you do not feel comfortable answering particular questions during the interview, you may share this with the interviewer.

What Type of Personal Information Will Be Collected?

Should you agree to participate, you will be asked to provide your current age, age at the time of your parent’s ABI, sex, current education level, current age of your parent, age of your parent at the time of the injury, sex of your parent, the severity of the parent’s ABI, diagnosis of ABI, and cause of the parent’s injury. In addition, personal contact information will be collected such as your phone number and e-mail to ensure that the researcher is able to contact you regarding the interview and review process. Furthermore, you will be asked to provide a pseudonym for yourself. The names of your family members and any agencies or organizations mentioned will remain confidential in an effort to protect your identity. The transcripts will reflect these changes. However, your relationship with your family members (i.e., brother, sister, mother, etc) will be used to help identify their relationship to you. You may be quoted in written or oral work; however, you will only be identified with your pseudonym.

The pseudonym I choose for myself is: _______________________________________________________

Are there Risks or Benefits if I Participate?

You need to be aware of the potential risks associated with your participation. Given the information that you will be providing, there is a possibility that those who know you may be able to identify you despite the use of a pseudonym. Although the researcher will try to prevent this occurrence by combining your information with others, there is possibility that you may still be identified by individuals who know you well. Furthermore, the online interview is being administered by Skype©, a division of the American software company Microsoft. As such, your responses are subject to U.S. law, including the USA Patriot Act. The risks associated with participation are minimal, however, and similar to those associated with many e-mail programs, such as Hotmail© and social utilities spaces, such as Facebook© and MySpace©.
In addition, it is possible that any discussions, interviews, or review of the individual depiction may raise dormant concerns that were associated with living with your parent with an ABI. Furthermore, it is possible that the interview may become upsetting as the past is re-experienced through memories and by sharing your experience. If this does occur you are encouraged to contact one of the community agencies mentioned below to access counselling services. If you are participating in an online interview, a list of accessible counselling services in your area will be provided to you.

1. The Distress Centre (24-hr Crisis line) Free (403) 266-1605
2. The Calgary Counselling Centre Sliding-Scale (403) 265-4980
3. Catholic Family Services Sliding-Scale (403) 269-9888
4. Eastside Family Counselling Centre (Walk-in) Free (403) 299-9696

Furthermore, if there is any mention of current incidences of child abuse, abuse of a dependent person or person in care, self-harm, or harm to others, the researcher has an ethical and legal duty to protect. Therefore, the researcher will break confidentiality and report these incidences to the appropriate authorities (e.g., social services, police, etc.). For clarity, the definition of abuse includes sexual, physical, emotional, neglect, and financial abuse.

In addition to being able to share your story and experience living with your parent, you will receive a $20 honourarium as a thank-you for sharing your experience with the researcher and contributing to the research. Furthermore, each participant will receive a summary of the findings.

What Happens to the Information I Provide?

Participation is completely voluntary, anonymous, and confidential. You are free to discontinue your participation at any time during the study. The audio-recordings and transcripts will be kept confidential. No one else but the researcher and her supervisor will have access to or hear the audio-recordings or transcripts. However, an anonymous data set may be made available to researchers and colleagues provided that that the research project that requires this information is given Conjoint Faculties Research Ethics Board approval. The findings from the current research project will contribute to a final Master’s Thesis that will be published upon completion. Furthermore, the findings will also be presented at academic conferences as well as in academic publications. All the participants will be provided a findings summary without identifying information for educational purposes.

All interview recordings, transcripts, individual depictions, and any other sources of data will be locked in a cabinet only accessible by the researcher. All electronic information will be securely stored by encrypting the files. These files will only be accessible by password, only available to the researcher and her supervisor. All electronic files will be stored on a separate hard drive and will never be stored on a computer. All the data will be archived and stored for 10 years at which time it will be permanently destroyed by permanently erasing any electronic files and shredding all paper copies.

Signatures (written consent)

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this research project, and 2) agree to participate as a research subject.
In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant’s Name:  (please print) _____________________________________________

Participant’s Signature ______________________ Date: ____________________

Researcher’s Name: (please print) ________________________________________________

Researcher’s Signature: ______________________ Date: ____________________

Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact:

Ms. E. Aiofe Freeman
Educational Studies in Counselling Psychology, Faculty of Education
Phone: 403-461-2769, e-mail: efreema@ucalgary.ca

AND

Dr. Sharon E. Robertson
Educational Studies in Counselling Psychology, Faculty of Education
Phone: 403-220-6542, e-mail: sroberts@ucalgary.ca

If you have any concerns about the way you’ve been treated as a participant, please contact the Senior Ethics Resource Officer, Research Services Office, University of Calgary at (403) 220-3782; email rburrows@ucalgary.ca.

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.
Appendix D: Sample Analysis Chart
<table>
<thead>
<tr>
<th>Themes</th>
<th>Issues (Meaning)</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Voice (being heard or unheard)</strong></td>
<td>Being unheard, ignored voicing concerns frequently heard, etc.</td>
<td>“I felt like my voice wasn’t being heard. And like, how I was feeling wasn’t being cared about. (School Guidance counsellor/teacher) and the family I lived with for 4 months after were those people for me (to hear her). And, I think that that’s probably the most important.” – Rebecca (line 840). “They (parents) live together but they’re not remarried or anything like that. But they, like, didn’t keep us in the loop, until way after the fact. “Oh, well this is what was happening”, kind of thing… you wouldn’t even get, social cues that things weren’t going well, besides having them not living together.” – Jessica (line 263) “Then my grandma got mad at the doctor. He came and pulled my aunt out of the room and said, “(Aunt) I need to speak with you.” And my grandma said, “No. You will speak to her in here. These are (mom)’s kids, and they need to know what is happening. Anything you can say to her, you can say in front of these kids.” – Tammy (line 171)</td>
</tr>
<tr>
<td><strong>Sense of being busy, few resources</strong></td>
<td>Money, time, energy, etc.</td>
<td>“My mom couldn’t help provide (financially) obviously, and my dad he has a good job, but he doesn’t get paid enough to support 5 people a lot of the time. So, money is always tight. And my sisters, they were too young at the time.” – Penny (line 187) “It was challenging to keep my job and keep the house and go to school and keep my commitments and be connected to my mom and (stepdad) in Calgary. It was very busy.” – Tyson (line 422). “Parking costs tons of money and gas costs a lot of money, so then you got money problems and like, everything was adding up.” – Jason (line 197)</td>
</tr>
</tbody>
</table>
“Like, busy a lot. And hard, you get frustrated. You get angry, impatient, anything like that. Plus, we always had to meet with the doctor so that they could talk to us about mom, and that would take time out of your day. And then, it’s just everything. We’re not getting enough sleep. Everything like that, while still paying for everything to get up there and back and still like, moving to a new house. Because we lived with my grandma right away. So we had to get stuff from our old house and it was a lot of frustration.” – Jason (line227).

“(less) Money and just being so busy and you just want things to slow down, kind of thing. You just kind of want to take a breather, and work on your own time. But you gotta work on everybody else’s. So, that was just basically the hardest thing.” – Jason (line233).

“You always gotta have money, you gotta have a job and money to afford things. So when you don’t work and you gotta go to the hospital every day and get through it, and go see and do so many things, money is a big play in it. Like they always say it doesn’t matter… You can always make more money, but not at that time.” – Jason (line 647)
Appendix E: Sample Individual Depiction

Jason

Before it happened, it was like any other family. I think we were a pretty normal family. Me and my sister were both involved in sports and all that. I thought some of the rules were pretty strict, and my mom was pretty stubborn about her rules. I mean the rules, you couldn’t break them or you would have some serious consequences. It was fine because I grew up like that. I could definitely tell the different between me and my friends for rules though. There was no missing family dinners because you have plans with your friends. I hated that at the time.

I had just turned 18, just graduated high school and was working full time. I was out a lot with my friends, going to the bars, and getting into some trouble here and there. Then it happened. My mom, dad, aunt, and grandfather got into a car accident the day after Christmas. My dad and granddad didn’t survive the accident, while my aunt walked away to call for help. My mom survived, but was severely injured. Mom was 42 years old when she got into the car accident. She was in a coma for like 8 months.

At the time, I didn’t really think about my aunt surviving because my mom was in such rough shape and my dad and granddad had died. But I realized later, that I was so happy that my aunt was at least ok. I think it kind of gave me a bit of hope that my mom could walk away; there is a chance. I think her surviving helped a lot. We at least had my aunt. When she was at the hospital or when she was working in the same hospital, she would come down and sit with us, and that helped us a lot. It was like, she got it. We shared the same kind of pain and we could just be. She helped us so much through the
whole thing. She became my mom’s primary caregiver too, and she really took some of the weight off our shoulders. I am so thankful that she made it out ok.

At first, I knew everything was not ok. It all hit me at once when I found out my dad passed away. That was horrible. But then, my mom was in a coma, so I almost didn’t put all my attention into grieving for my dad. I was still directing most of my attention to my mom. But then we had to bury my dad and we wanted to wait until my mom came out of the coma. A couple weeks after, people would be like, “you ok?” and I’d be like, “Yeah, I’m fine”. Just to brush it off when I thought about it. I definitely didn’t want to lead on that things were not ok for a little bit. Four weeks later she wasn’t awake, so we just buried him without much of a ceremony. That’s when I think it hit me the most. We had to pick out a tombstone and all that stuff. After denying it for a while, it kind of just all hits at once all over again. We realized that our dad passed away and that was still hard, but the fact that my mom didn’t know was kind of the worst part.

The hardest part of the experience was thinking that my mom wouldn’t wake up. I know I thought about what I would do if it wouldn’t ever get better, and if it just stayed the same. I kept thinking that I would just get used to it, but I didn’t know what was going on. I think not knowing what was going to happen was really hard because I couldn’t do anything. It just kept going, wondering day to day if maybe she would wake up that day. I couldn’t focus on anything because, when she was in a coma it was always in the back of my mind that she’s still in a coma. So I never really gave 100% to anything, and never really commit to anything because there’s still that one commitment that is the biggest: my mom in a coma.
Right after the accident, it was really hard. Everything was hard, and nothing seemed to go the right way that you wanted it to. We just slept there, ate there, all that kind of stuff. But, it was hard, like nothing was in place, nothing felt right. There was a lot of support from everybody – my family and friends mostly – but at the time, right at the initial time, it didn’t matter like who gave you support or anything. It felt good but it didn’t change anything. I was sad, hurt, and aggressive sometimes, like angry. It was like every kind of feeling, I felt. It would change for 5 minutes where I would feel better about things and when someone new would show up at the hospital to help out. Then my feelings would just come back. I always expected it to get easier, but it didn’t for a long time – maybe after the first 4 to 6 months. Everyone was always crying. It was hard for me to feel better when everyone around me is crying.

On top of everything, I was 18 so everything in my dad’s estate went to me, and I really didn’t know what I had to do with it all. I had to deal with what will we do with my dad, and what will we do with the legal stuff and the house and all the bills that weren’t paid. With my grandma and my aunt, they were the main people that helped my sister and me. They called around and told the insurance companies and banks what happened. People were pretty understanding when they found out what had happened. We had to go meet with the banks and close down my father’s account and stuff like that. Stuff that you don’t want to do but you kind of gotta do it. I had to be there for all of it, until we met with the lawyers to get my aunt to do it. It was a hassle, because it’s the last thing you want to deal with. At the time, all I wanted to do was just stay at the hospital. Be with my family, go see my mom, and see how she’s doing. But I have to deal with all this stuff, and leave the family at the hospital. My family kind of had more respect for
me, I think, because I took all of this on. They saw that I could do it and I think I really stepped up to the plate.

I’d say until about February, I was at the hospital every day. There was no working, just the hospital every day. Family would come down and all that kind of stuff. I would be talking to the doctor about my mom a lot and so I had to deal with things right away. It was like, this is real, I have to deal with this and take care of things. I always had to be there for the meetings. Then I still wanted to look out for my sister. She’s number one, still is. Anything that got brought up though, it would always be about the accident, so it would always make me sad and make me hurt. There was never really any happy things that would happen for the first little bit. Because bad things kept being brought up, and I would keep getting so sad. But I had to go with it, and you can’t back away from the bad things. It’s kind of something you have to go through.

I went back to work in March because I was dealing with some money problems. Part of the problem was that I had to go the hospital every day, which costs money with parking costing tons of money and gas costing a lot of money. I had some problems at work though because I would start thinking about my mom and what we don’t know and that would all come up, so then I couldn’t work. I couldn’t pretend like everything was normal, and I couldn’t stop thinking about what was happening. So at that point, anything to keep my mind off of it was kind of the best thing at the time. I needed something outside of the hospital to keep me on top of things. At my work, it was really nice that I could just do my job. Even if people knew what had happened, they didn’t ask me about it and left me alone. If I wanted to talk about it, I would, but they mostly left me alone.
I would think a lot about my dad as well and at first, it seemed like anything someone would talk about, I would think about my mom and dad. Like the simplest thing. For my dad, I would be at Canadian Tire or something, and I would see a pair of skates which would bring everything up again. My dad taught me how to skate when I was younger, so I would remember things like that, triggered by other things like watching hockey. My relationship with my dad was a lot better than with my mom because it was father-son kind of thing. There was a lot more things my dad and I would do together. He taught me how to play hockey, and he was my coach for all of the 12 years I played hockey. We worked on cars on the weekend, too. He would show me how to do all the guy stuff. When it came to play, my dad was definitely the easier person to talk to. But when I got in trouble, my mom would deal with me more than him. Dad would discipline me, but like in a joking manner. My dad wouldn’t get as mad as my mom.

My relationship with my mom was good, like anybody else. She kind of kept us on track. She taught me how to spend your money. She would guide me, and tell me what to do, like “this is wrong, this is right,” and whatnot. She was kind of like the rule holder. If it was bad trouble, she would tell me what to do. Usually it didn’t seem right at the time, but it would always be the better choice. She gave the advice that you wanted to take. Anything, play or discipline, always went through my mom. She would make the decisions about how to punish me. After the accident, it definitely changed a lot.

My close friends were great too. My best friend at the time lived with our family for about 2 months before the accident because he got into a big disagreement with his parents. So he was really close to our family and he stayed in the hospital with us for the
first three weeks. That helped a lot. The rest of my friends knew what was happening and they would let me talk about it as I needed. They would know what buttons to push and what buttons not to push. They would almost know when you wanted to talk about something, and they would know what to say and what not to say. Instead of being like, “what happened?”, it would be like, “how’s your mom doing?” Throughout the whole experience, they always kept my mind off of things. My friends knew how to make me laugh. We go and do things like we go hunting or camping, or anything like that to keep your mind off things. Even go to the bar and getting drunk one night, takes your mind right off of it. Instead of staying home with my family and looking around and saying where’s our mom. You have fun and that was the best part. They helped a lot that way. They helped me not be so angry and actually accept that I could be sad, I could be hurt, I could be frustrated.

Everyone in my life pretty much left me alone, so that I could basically deal with things in my own time, when I wanted to, not when other people wanted me to. It would be some stranger or people that I didn’t really know that would be like, “I heard this, is this what happened?” And they’d bring it up and you’ve got to give them an answer. You can’t just brush it off like you can’t just think about it. My friends would help me with this and sort of protect me because I used to get really angry about this. It was like, why are you asking me this? Get off my back, I just want to have fun. It would put me into a bad mood. My friends would come by and calm me down or remind me that we can leave and talk if I wanted. Eventually, I realized that people were asking because they didn’t know any better. It is still a trigger for me now, but I know that they don’t mean anything by it.
It was really hard balancing everything going on in my life. Life doesn’t stop when you deal with this kind of stuff. You have to keep working; you have to be there for your family; you have to keep your friends; you have to keep going. So I was busy a lot. I got really frustrated a lot because I was really hurt inside and had to manage money, and being so busy, and all I wanted were things to slow down. I wanted things to be back to normal. I would get angry, impatient, and anything like that. I wanted to take a breather and do things in my own time, but I had to work on everyone else’s time. There were no sit down and eat dinners. They were always dinners where you’d be running out of the house with food in your mouth. We had a lot of support from other families, like the hockey parents. But dealing with the lawyers, doctors, family, and friends that all wanted to see you and just everything. It was just busy all the time.

Then, you have to take care of yourself, but that doesn’t happen as much. It’s just everything. We’re not getting enough sleep. I don’t know how my sister did it because she still did well in school. Eventually, I realized I couldn’t do it all, and it was too much to be in the same house, after everything that had happened. So we moved to my grandma’s house to help with the bills and all that. We didn’t really want to leave, but we had to. It was too hard on us and really frustrating.

After we moved in, my grandmother got worried about us and wanted us to see this therapist person. At first, the doctors recommended the people that told us about our father when he passed away. But obviously we had a hate for her because she was one of the first ones who told us what happened. So we obviously had negative energy towards her. Then I think my sister went for a few sessions, and I only went to like 2. I think the best way that I dealt through it is just family basically. A lot of family and friends.
Talking to a complete stranger about something that the person couldn’t possibly get. That was in the back of my mind, like how’s she gonna help me when she has no idea what this is like and she’s never been through it. It’s kind of like, I decided I had to work myself through it. That’s eventually what I did. If there was a counsellor out there who had maybe been through the same stuff and knew what to say, then I would be more willing. But it seemed to me like counsellors are sometimes pushy. They want you to say what’s on your mind, even if you’re not ready to say it. Sometimes it’s just not the right time for it. If there was a counsellor who took their time, who maybe had specialized in this kind of stuff, then I think I would have definitely gotten more out of it.

After she woke up, things started to get better. I don’t think I fully accepted things until my mom woke up. She was making progress, even if it was slow, we still had her. I think what changed is that now I had hope. A lot of the time, my grandma would look at me and be like, “there’s no life in your eyes.” Around certain times, I never really smiled much. But mostly, when my mom woke up, it changed a lot. I was happy again. I changed and started going back to the person I used to be. I started doing the same things, getting excited over the same things, and actually participate in life again. I could actually there for family conversations and stuff, not mentally wandering off and thinking about my mom and dad.

My sister and I were supposed to tell my mom that our dad had passed away, but we didn’t. We got out of it because we just couldn’t basically. But after that, I grieved with my mom, but it was hard because we had to do it when it actually happened and then 8 months later when we were almost done with it. It had to be brought up again. But it was a lot easier going through it the second time. We could give her advice and
you know actually help and sit with her and talk to her, and stuff like that. That really worked out well. Having her awake helped us a lot too, because now we knew she was going to make it out of it. She was still with us and we didn’t lose her too. We had a proper funeral where it was a celebration of his life when my mom woke up. But it was still tough doing it twice. What would have helped us a lot at the initial time when it happened was having a parent. I think that would have helped a lot.

Being the oldest left me with no one to turn to for guidance. I had my sister but we were both lost. It would have been nice having someone there that has been through the same thing or almost the exact same thing and who I wasn’t related to. I think would have helped so much. Having someone that knew what you were going through and how to go through it, knew what to look forward to, and knew when to talk. They could give you advice that would work and guide you through everything so we weren’t so alone. I think seeing them make it would have been inspiring at the time so it didn’t seem so hopeless. It would give me hope to see that they made it, so that means I can too.

My mom was still at the hospital for 2 months after she woke up. So I still went to the hospital every day, but instead of going to the hospital hoping my mom would wake up that day, I got excited. It was exciting to go to the hospital after work. I could talk to her again, and she was awake. I would be even excited to talk to my friends and tell them what she’s up to now too instead of “oh she’s in a coma” all the time. We would put her in a wheel chair and take her upstairs to go eat with her and stuff like that. That was pretty cool. I got excited to see what kind of progress she’s made each day. Considering we were told that she could have been a vegetable when she woke up and that she wouldn’t remember us. When we saw her remembering us, and asking us how we are
doing, it was exciting because we were as prepared as we could be for the worst case
scenario. As far as we know she remembers everything except for a year and a half
before the accident. So bringing up and talking about old stories wouldn’t make me sad
any more. We could bring up funny stories and it would make us laugh, “remember when
this happened”. Her actually being there to participate is awesome. The doctors always
told us the worst case scenario so we would feel more prepared and more excited when
she surprised us. When she woke up, she could move her hands and she would laugh,
which was so amazing.

She was different when she woke up though. Before the accident, she was
definitely the rule giver. If you asked her for money, she’d be like, “you have to ring me
up a plan of how you’re going to pay me back.” Now, she’s much more relaxed about
those kind of things. If I ask her for money to get rollerblades or something, she would
just say “ok here you go”. It almost seems like she’s decided that life’s short so no point
getting upset about things and no point not taking those chances. Before the accident, she
wouldn’t really go on vacations. Now she takes us on vacations all the time. She’s been
on like, 5 different trips. It’s like she wants to see the world so she’s going to see the
world and she’s doing things she’s wanted to do for a while. She taken this mentality to
us as well, and she’s not holding us back. There’s no like, Oh you don’t have the money
for it, so you can’t do it. It’s like here’s the money for it, go do it. Live your life, have
fun, and enjoy yourself. I think she understands that me and my sister went through like
the same hurt as her and she wants to make sure we live life too.

She also asked a lot of different questions like how we coped at the beginning. I think
the worst question was “what if it was me, not your father?” I would always tell her that
it wasn’t. I didn’t want to go there, and I was thankful she was with us. I’m not saying
that I don’t want it to be him, I don’t want it to be you, it’s just it wasn’t you and this is
how it happened. So we have to deal with it as it has happened. I think it hurt her that she
missed 2 years of our lives almost. She was in Ponoka for a rehabilitation program for 2
years after she was released from the hospital. She didn’t miss it entirely, I don’t think,
but I think she thinks she missed a lot. We would talk a lot on the phone while she was
away and then she would come back every weekend. She didn’t want to be there because
she missed her family, and she would cry when she would come home for the weekend,
and she would cry when she had to go back. We would all cry really, but it was the best
thing for her. We had push through that. Because of that rehab place, she’s so much
more independent. My grandma and aunt were a lot of support in this time too.
It has been harder to understand my mom now than before. Before the accident, she
would say something, and it would make perfect sense. Now she sometimes leaves out
certain details. So you have to put it together by yourself because her brain isn’t fully
working in there. I went back to playing hockey and this gave me an outlet for dealing
with everything and all of her changes. But everything down to the littlest thing is
different about my mom. My sister and I had to get used to this. We had to realize that
things were never going to go back to normal again.

My sister and I get along a lot better now. We are really there for each other,
even now. Before the accident, when we were younger, it was obviously good. But then
we hit high school, and we’d hang out with different people and different kinds of
groups. That kind of split us apart. We would spend a lot of time our friends and not at
home as much. We would fight a lot and whatnot. I was her “big brother” in high school
and took care of here where I could. I would look out for her even though we didn’t really get along. When we moved out and after the accident happened, we became a lot closer. Basically, we grew up, and we matured. When we used to fight it would be over really dumb things, but now we focus on what’s important and what’s not. So we just basically grew up together and went through the accident together. She became my big sister too. We took care of each other. We both experienced the same thing. It was easier to go through that with my sister than with my friends. That was a big part. That’s what made us a lot closer after the accident.

I’m 22 years old now, and I think I have accepted the fact that my dad passed away and that my mom will always be different. She’s still my mom. I’ve changed so much because of this. I don’t want to disappoint anybody, let alone my family, when before the accident, I didn’t care. Now, I want to make everybody happy. I don’t want to walk into my friend’s house and them be like, oh that’s the kid who broke a window, or something like that. I don’t want to be like that. I want everybody to be like, look at him, look at what’s happened since the accident happened. He didn’t go downhill into like drugs, and he didn’t go downhill to like, partying or gambling or anything like that. He improved from it, and it made him better as a person. So that’s what I’m going for. A lot of people say it’s working. Hearing this from my friends is so awesome to hear because they’ve seen me at my worst and now. Don’t get me wrong, people might still look down at me, but I don’t really care that much. I know who I am and I know I’m a lot better of a person than what I was before. I’m doing a lot better for myself. I have a great job and not a lot can bring me down now. If I can change their opinion of me, then I will
definitely try, but I don’t let these things get to me. They have their opinion and I have mine.

Looking back on things now, I realized I had to mature so quickly. I had so many more responsibilities in such a little amount of time. It was really hard at the time, but it helped me out a lot. A lot of my friends are just maturing now. I did it when I was 18 in a moment, because I had to. It wasn’t easy to grow up right away. It was really hard at the time. I think I stepped up because of my family upbringing – you always got a job, you always have to have money to afford things. They always say it doesn’t matter, and it doesn’t matter that much. You can always make more money, but not at that time. Everything was hard and you had to get through it -from the littlest things to the biggest things. Like I would listen to a song and I would not care at all if it was just generally country which is what my dad really liked to listen to, but to this day, I cannot listen to my dad’s funeral songs. But my sister can listen to stuff like that now. Everybody’s different, right? There’s a lot of things that would hold you back and that would make it that much harder. Once I get through those really hard things, it started to get easier. I’d say the best advice anyone has ever given me was that everything happens for a reason. That really helped me through, and so I wanted to make the best of it.

I’m a better person now, I think. I’m not going to say that I’d be different or doing worse if it didn’t happen, but like there’s a good chance that I would be in trouble by now. I’m not going to say it was a good experience, but I learned a lot from it. It made me do things a lot more, not only for myself but for what people would expect of me too. I would think; if I were doing something bad, what would my dad think? What would he think of me now? And I think he would be amazed that I’ve stayed out of jail for 4 year,
and that I went to SAIT and actually graduated high school and did something, finished something. I think it’s got a lot to do with it – he keeps me in line still. My family can rely on me now. If someone needs something done, they know I will do what I can to make it happen. I realized what’s more important in life. Realizing that being cool, smoking, or anything like that in high school has got nothing to do with how it’s going to affect your life. Like, it’s not important. It doesn’t matter. You want to do something, then do it. Don’t think about it for like 5 years. I think I have a different perspective now about my life, and that life is too short to worry about stuff like that. I could die tomorrow, and so I’d best make the best of today. Do I want people to remember me like a bad kid, or do I want to make people proud?

I think recognizing the hopes my parents have for me really is what made me change. I always want to fulfill their dreams for me. Since the accident, I think I just really got it. I wanted to have a good job making good money just because my dad told me that I have to get a job. My car breaks, I can fix it because my dad taught me. My friends say that I give them hope for bettering themselves, they know it’s possible. Then I look up to my sister and go, wow, she graduated high school, did well on her exams, and all this, so why can’t I do it too. What she had to do seemed a lot harder to me, and so I thought if she could keep herself on track, I could do it too. If it was hard for me, I can only imagine how hard it was for her with a million things on her back. When you think you have it really bad, other people always have it worse. I could have lost both my parents.

I didn’t want to spend so much of my time angry. Really, after losing my dad, my granddad, and almost losing my mom, I need to make sure I enjoy life. I can’t get mad at
people like I did at the beginning. I’d regret every time me and my parents used to get into a fight. When I got kicked out for like two weeks, I regret that 100% now. Not saying sorry and just acknowledging that what I did was wrong. If I’m going to be sad, it’s not going to change anything. Same with being mad or upset. So just get over it and be happy. Sometimes you can’t, of course. But for the most part, stupid little things that bring people down, I just kind of brush it off. When my friends would get mad, I’d be like - I don’t know why you are mad at that. It sucks, but you can be mad and let it ruin your day or you can have fun.

My mom’s family is Lebanese, and my dad’s is mostly Canadian. The family is really close now. It’s a big family, but really close. I definitely see our grandma and our aunt and uncle more. We were close before, but after the accident, we are a lot closer, especially with my dad’s side of the family. Because they live 2-2 ½ hrs away, we didn’t really see them all that often. Just like every other year at Christmas, but now we see them a lot more often since the accident. They live in Arizona and Edmonton, but we still see them like, at least three times a year. This is really nice because it’s always nice to have more family around you, supporting you. Now, I can go see my family and have some fun, like going to weddings and even funerals. It is always nice to see them and I always feel good inside after. I don’t miss family parties anymore because there really isn’t anywhere else I’d rather be. We are so much closer now.

I think I’ve accepted everything that’s happened and probably recently too. There are still touchy subjects, but not so touchy that you break down, and it would ruin your day. Now, something gets brought up like a story at camping with like your friends’ friends. You’d have fun talking about him. It took some time to get there, but it was
good. My mom never disappoints. Every day she keeps improving. She is learning more every day. Now she’s trying to walk and it keeps getting better every day.

**Words of Advice:** Honestly, I would just give them my number. If they were a friend or someone I knew, I’d be like, here’s my number, like call me if you want to talk. I’m not going to tell you to come talk to me, but if you want to talk, I’ve been through the same thing, so call me if you want to talk. I hated being pressured into it, but when I wanted to talk it was always nice to have someone there. So I’d probably just make sure they knew I was there and whenever they wanted to talk. If they are feeling extra down one night, just take them out and have a few drinks and hang out with a few friends something like that, just get their mind off of it. If I didn’t know them, I would want to tell them that it gets better. It takes a while but it will look up. I think the thing that made it take so long was that you expect that everything will go back to normal. But it never did. It’s as good as it was normally, but it never went back to the normal we knew. And that takes a lot to set in.

I would probably tell them that everything happens for a reason, but they probably don’t want to hear that at the time. But, I probably would tell them that, you can only go down so far, and then you gotta go back up. Look forward to the good things. If the doctors tell you that she’s not going to wake up, don’t believe them. Believe in your mom, not the doctor. Don’t stay on the bad things for too long because that doesn’t help you. And the good things keep happening, so keep looking to those good things.