

ADOLESCENT RESPONSE TO PARENTAL TRAUMATIC  
BRAIN INJURY AND AMBIGUOUS LOSS

by

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## ABSTRACT

WILLIAM RAY LEACH. Adolescent Response to Parental  
Traumatic Brain Injury and Ambiguous Loss  
(Under the direction of DR. DREW POLLY)

Parental traumatic brain injury (TBI-P) and the effect it has on adolescents living in the home has been mostly avoided in the current literature. Even more rare in the literature is the idea of ambiguous loss, coined by Boss (1991). An ambiguous loss refers to a loss of someone who has not died, but who is also not the same person as before the injury, physically or mentally. Consequently, the loss is unclear and requires constant recalibration by the uninjured family members to accept their ever-changing injured family member. Together, no researcher has ever studied ambiguous loss as it relates to TBI-P.

This study focused on three research questions:

Research Question 1: As it pertains to TBI-P, what is the influence of ambiguous loss when experienced during adolescence?

Research Question 2: When TBI-P is experienced in adolescence, how does the perception of ambiguous loss result in tangible consequences later in life?

Research Question 3: In what ways do adolescents experiencing ambiguous loss from TBI-P describe their family, self, and situation?

Using a qualitative approach, this phenomenological dissertation found four primary findings. First, adolescents can experience feelings of ambiguous loss. Second, the time since the injury can affect the severity of feelings of ambiguous loss in adolescents with older participants reporting more feelings of loss. Third, adolescents can experience tangible outcomes as they relate to TBI-P during their adolescence and into adulthood. Finally, ambiguous loss can affect the self-perception of adolescents.

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In 2002, I decided to walk out of the doors of my high school and drop out. I was distracted, under pressure, and feeling lost in math and science. At the time, I figured I would get a good-paying job and that an education was worthless. Thank goodness I was wrong. As I worked my way back up from a GED to a Ph.D., I cannot help but look back and offer appreciation for the people in my life who would not let me quit. I would like to acknowledge those people here, as a small token of appreciation for their impact on my life. I would not be here without you.

To Mr. Gillespie, my sixth grade science teacher: you realized I was acting out in class for a reason and when you pulled me into the hallway that day, your words made an impact on my life. I knew then that I could not continue down the same path I was on, and your redirection was exactly what I needed to get my attitude in order so that I could be successful later in life. To Dr. Meg Morgan, your English courses in my undergraduate years at UNC-Charlotte first gave me the idea of getting a Ph.D. Your teaching style, your personality, and your passion for teaching ignited something inside of me. To Dr. James McGavran, your excitement for British literature and your loving spirit showed me that there is room in higher education for folks like us, the dreamers and the young at heart. May you rest in peace.

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## DEDICATION

This project is dedicated to my father, Robert Franklin Leach, who passed away in 2012. Dad, I know you struggled through life while you were here. The brain injury you sustained really challenged us and we did not know how life would end up. Through it all, even in the challenging times, I saw you as one of the most loving and supportive dads in the world. You always believed in me, always invested in me, and always loved me, no matter what I did. While this life can be cruel and your death was so very unfair, your memory lives on. I hope this dissertation makes you proud. See you soon, dad. I love you.

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## LIST OF ABBREVIATIONS

TBI	Traumatic Brain Injury
TBI-P	Parental Traumatic Brain Injury

## CHAPTER 1: INTRODUCTION

In 1994, my father fell from a machine at an auto mechanic shop where he was employed. The machine, which lifts cars off the ground for service underneath the vehicle, was approximately 16 feet off the ground, directly over a set of concrete steps that went down to the basement of the shop. When my father fell from atop the machine, he landed head first on those concrete steps and suffered a moderate traumatic brain injury (TBI) with penetration to the back right side of his head. He was rushed to the hospital where the doctors were surprised that he was awake and able to communicate with them, sitting up with no discernable symptoms aside from the physical head injury itself. Since there is no official term for a parental traumatic brain injury as referenced throughout this study, the abbreviation TBI-P will be used and refers to a TBI that occurs to a parent while children are living in the home.

At the time, our family was told that people do not normally survive a fall from those heights with a penetrating head wound. As time progressed, the psychological consequences of his fall would emerge. Since that day in 1994, my life was forever changed as my dad was released from the hospital as a different person than who entered. Besides blinding migraines that kept him in bed in a darkened room for days on end and unable to eat or move without debilitating pain, his personality changed him into someone I occasionally did not recognize. Instead of love and laughter, there were extreme and quick mood changes along with a widening sense of distance between him, my mother, and our family unit. Consequently, the psychological changes he experienced would often result in heated arguments with my mother that would often dissolve into shouting matches, suicidal threats, or threats of divorce.

As a 5th grader, I was suddenly thrust into the position of playing peacemaker between my parents while simultaneously dealing with the reality that my old dad was not the same

person I would be interacting with moving forward. Simultaneously, I was dealing with attending school and attempting to balance my studies with my new reality at home.

Consequently, school and homework became secondary as I began to experience negative changes in my injured father. My mother was tasked with caretaking and unavailable to focus on my declining educational and behavioral issues at school, setting the stage for years of educational struggles. Eventually, I would fail 8th grade and drop out of high school in the 11th grade. Consequently, my relationships with both of my parents disintegrated for a time, causing me great stress and internal turmoil as I navigated the crisis. This change in relationships is well documented in the existing literature. Researchers are aware that adolescents experience major stress as parental attention decreases (Klonoff, 2014; Dix & Meunier, 2009; Kieffer-Kristensen et al., 2011; Uysal et al., 1998). As families are tasked with becoming primary caregivers post-injury, they are almost guaranteed to create new family roles and expectations to accommodate the injured parent and to create a new sense of cohesion amongst family members (Verhaeghe et al., 2005; Florian, Katz, & Laman, 1989; De Marle & Le Roux, 2001). As the literature shows, my mother, like others in my situation, could not support me as much as I needed since she was supporting my father which caused me to essentially work through my emotions and school issues on my own. Through no fault of her own, I understood even at that time that she was put into an untenable situation and that her attention and personal resources were being pulled in many different directions that would not be sustainable.

During my middle school years, I visited the counselor's office at school numerous times but did not receive the support I needed since the counselors did not know enough about traumatic injuries to be of any real service. For example, I would talk to the counselor for a few moments, have a good cry about my situation, and be sent back to class; they did not know how

to help me, other than to listen. Throughout the years immediately following the injury, I would visit a psychiatrist that was recommended by my father's neurologist and we would talk about my experience and ways to work through my feelings. Other than a handful of visits, I never had the opportunity to speak to anyone who understood or could empathize with what I was going through. The unavailability of professional support as an adolescent experiencing TBI-P aligns with the literature that shows such supports are often only available to primary caretakers. These personal changes, too, are supported by the literature from the field, and much of it hinges on the concept of ambiguous loss. Boss (1991) defined this term as ongoing and conflicting feeling of loss of a still-living person. Boss (1991, 2006) found that when a family member is injured and psychologically and/or physically changes into someone different, families of the patient must mourn the loss of the old person while simultaneously accepting the new version of that person. Compared to fatal injuries, which allow for some semblance of mourning and closure, an adolescent who experiences a traumatic event, such as a TBI-P, does not have the opportunity to experience closure since the injured person is still living. The literature surrounding ambiguous loss is still in its infancy but well supported through studies on stress (Visser-Meily et al., 2005; Kieffer-Kristensen & Johansen, 2013) and disrupted parenting (Klonoff, 2014; Dix & Meunier, 2009).

As I entered the classroom space as a middle grades English teacher, I was keenly aware of how trauma could manifest in ways that are represented as behavioral problems such as acting out, disrespect towards others, and a general passiveness to academic enrichment activities, like homework or classwork. Consequently, as a teacher, I began to wonder how traumatic events interact with students in their school setting. Costello, Fairbank, and Angold (2002) found that approximately more than a quarter of children and adolescents experience a traumatic event by

the time they turn 16. Researchers know that exposure to a traumatic event can lead to post-traumatic stress symptoms (Angold, Costello, Farmer, Burns, & Erkanli, 1999), symptoms of anxiety, depression, and disruptive behavior disorders (Copeland, Keeler, Angold, & Costello, 2007), and higher chances of dropping out of high school (McGloin & Widom, 2001). If an adolescent experiences a TBI-P, how does their experience with ambiguous loss play out in their lives?

### **Traumatic Brain Injuries**

Traumatic brain injuries (TBIs) are described differently across the literature. Tiar and Dumas (2015) refer to injuries sustained to the brain from some type of external force. Alternatively, Degeneffe (2001) defined TBI as occurring when there is an external force that imparts damaging energy on the skull. The American Speech-Language-Hearing Association (n.d.) describes them differently, noting acceleration and deceleration injuries do not include any external force to the head. Yet others have defined them based on how the injury occurred and the severity of the injury (Cunningham, Chan, Jones, Kramnetz, Stoll, & Calabresa, 1999). As it will be used within this study, TBI is defined as any traumatic brain injury that results in a moderate to severe TBI, regardless of how that injury was sustained. A TBI is far more than a physical injury, but a producer of “distress and feelings of despair from patients and their loved-ones alike...that may cause serious changes in the patient’s personality, cognitive capacity and physical functioning” (Kieffer-Kristensen, Teasdale, & Bilenberg, 2011, p. 752).

TBIs have both physical and emotional consequences for the injured person and their immediate family members. Physically, traumatic brain injuries result in “tissue distortion, shearing, and vascular injury as well as destabilization of cell membranes and frank membrane destruction” (O’Phelan, 2016, p. 3). If the TBI is caused by an external force, the physical

damage sustained during a TBI event, depending on the severity, can lead to a lifetime of physical impairment, including debilitating migraines and other secondary injuries to the body, such as muscle hypertonia and sensory issues (Lynch, 1986). Some researchers have also pointed to the idea that unlike other traumatic events, there is a higher risk of complicating post-TBI concerns, including physical challenges that result from the injury, such as from a fall that injures the head and other parts of the body (Kieffer-Kristensen Siersma, Teasdale, & Kieffer-Kristensen, 2013). Psychologically, TBIs can manifest in both behavioral or emotional symptoms that can either resolve themselves in the days (mild TBI) or weeks to months (moderate and severe TBI) following a TBI, if at all (Bellamkonda, Eapen, & Zollman, 2016).

Long-lasting symptoms not only have an ongoing negative effect on the patient experiencing the TBI, but the family unit supporting the injured person is also heavily affected. While the primary family caretaker can find research and assistance to help them navigate their situation, most children experiencing a TBI-P are not offered assistance from professionals, with one study showing only 19% of rehabilitation staff included the children of TBI patients in their attempts to support the primary patient (Webster & Daisley, 2007). Some researchers found very few rehabilitation centers focused on children of TBI-P patients, noting a lack of programs specifically designed for them (Klonoff, 2014; Visser-Meily et al., 2005; Webster & Daisley, 2007). Consequently, some researchers have argued that children need to be involved in the traumatic event through counseling that includes the entire family and that is informative and appropriate for their age-based developmental stage (Dale & Altschuler, 1999; Allen & Hoskowitz, 2014). Whether or not adolescents are involved in the traumatic event aftermath, they can sometimes see their brain-injured fathers as having transitioned from self-sustaining

men to psychologically unbalanced men and it can create a devastating outcome for children in the study (Butera-Prinzi & Perlesz, 2004).

TBIs are well covered in the existing literature but far less attention has been paid to TBI-P and their effect on adolescent children in the home. While researchers are beginning to understand the role of stress in adolescents after parental trauma, less is known about the specifics of how a TBI-P truly affects adolescents as they also deal with a concept known as ambiguous loss. Ambiguous loss has been lightly researched in the literature but has mostly focused on adults and primary caretakers, not adolescents. The existing literature contains numerous research studies centered on TBIs and the detrimental effects they can have on the mental and physical well-being of the person experiencing the injury (Gordner & Tuel, 1998; Preventing Traumatic Brain Injury in Older Adults, 2008; Anderson & Yeates, 2010; Zollman & Barry, 2017; Heidenreich, 2018). However, there are few studies that speak to the experiences of immediate family members of these patients and few researchers investigate traumatic incidents from the perspective of the uninjured adolescent who is a secondary experiencer of the injury. Few studies explicitly examine a TBI-P event and the concept of loss for adolescents. Using the search terms described in chapter two, there is an insufficient number of studies that center on the experiences of children whose parent experiences a moderate to severe TBI and how the child processes the event and consequent life events following it; this gap in the literature serves as the catalyst for this research study (Butera-Prinzi & Perlesz, 2004).

### **Purpose of the Study**

The objective of this phenomenological qualitative study is to explore the intersections of a moderate to severe TBI-P and ambiguous loss, how the concept of ambiguous loss might result in tangible consequences in the lives of adolescents, and to explore how adolescents describe

their family, self, and situation in relation to the TBI-P. Phenomenology is focused on the essence of a phenomenon or what it is like to experience something, helping researchers discover meaning through lived experiences. The phenomenological approach used in this dissertation allows for the exploration of how adolescents describe their realities as they are related to the TBI-P, offering possible benefits for parents and educators as adolescents share their experiences. Perhaps most importantly, the abstract concept of ambiguous loss can be further explored and connected with events that follow a TBI-P event, tracing a path from injury to tangible outcome in the lives of the participants of this study. First brought to the literature by Boss (1991) and further researched by Boss (2006) later in her career, ambiguous loss is a complex phenomenon:

The ambiguity freezes the grief process (Boss, 1999) and prevents cognition, thus blocking coping and decision-making processes. Closure is impossible. Family members have no other option but to construct their own truth about the status of the person absent in mind or body. Without information to clarify their loss, family members have no choice but to live with the paradox of absence and presence.

This study will contribute to the literature by examining how a TBI-P event influences the experiences of non-caretaker, family members.

In the absence of a strong literature base that recognizes the adolescents' secondary experience with TBI-P, the concept of ambiguous loss was introduced as a means of explaining and giving voice to how a non-fatal injury has the potential to still create a sense of loss, even if the injured person has not passed away. When someone experiences a traumatic brain injury that alters their emotional, behavioral, or physical states, family members must constantly adjust to their shifting family dynamics and can never experience true closure in a similar way that a fatal

injury might allow. While a fatal injury could allow a family the eventual, although never guaranteed opportunity for closure, a non-fatal TBI-P requires family members to mourn the loss of their pre-injury loved one while simultaneously forcing them to continuously alter their evolving relationships with the injured family member (Gergen, 2006; Boss, 2006). As TBIs are the most common neurological events for the population under age 50, and consequently the most common years for child-rearing, TBI-P likely affects many children, "who have been identified within the literature as a high-risk, though neglected group [because of the TBI-P]" (Butera-Prinzi & Perlesz, 2004, p. 83). Researchers have long been aware that adolescents manifest their feelings and emotions emanating from a traumatic event and turn them into poor educational performance (Shonkoff & Garner, 2012; Levenson, 2017). Considering how adolescents are already in a physical and emotional transitional period between childhood and adulthood, it would be useful to investigate how they construct their realities as it pertains to their injured parent.

Using the ABCX Model (Hill, 1958), the theoretical framework used in this study is used to examine family stress as it relates to a traumatic event. Families must immediately respond to an unforeseen traumatic event, use their resources to successfully navigate it, frame the event as a positive or negative experience, and alter their role in the family. This model helps researchers determine how likely it will be that a family successfully navigates a TBI-P event. However, this study also considers post-crisis variables and, through the research questions, seeks to explore how adolescents adapt(ed) to the injury. With a focus on how ambiguous loss plays a role in the lives of adolescents, they could offer further insight into how ambiguous loss played a role in their lives in the years after the injury, how they define or see themselves in relation to the injury, and how their lives were changed in relation to the TBI-P.

## Research Questions

This study was grounded in the following research questions:

Research Question 1: As it pertains to TBI-P, what is the influence of ambiguous loss when experienced during adolescence?

Research Question 2: When TBI-P is experienced in adolescence, how does the perception of ambiguous loss result in tangible consequences later in life?

Research Question 3: In what ways do adolescents experiencing ambiguous loss from TBI-P describe their family, self, and situation?

## Significance

The significance of this study is to fill an existing gap in the literature as to how exactly ambiguous loss is operationalized in the lives of adolescents who experience a parental traumatic brain injury. While the term ambiguous loss has been defined in the literature (Boss, 1991) and mentioned in articles, the term has not been applied specifically to TBI-P in a phenomenological approach and focused on how adolescents process the event. Most studies about stress and loss tend to focus on the caregiver while other family members are secondary subjects of the study (Degeneffe, 2001). Other researchers also acknowledge that the literature is sparse on published data to show how adolescents adjust after a TBI-P (Pessar, Coad, Linn, & Willer, 1993; Perlesz, Kinsella, & Crowe, 1999; Verhaeghe, Defloor, & Grypdonck, 2005; Redolfi et al., 2017). For instance, Redolfi and colleagues (2017), in agreement with Tiar and Dumas (2015), found that there were minimal numbers of studies focused on how children adjust to a TBI. However, researchers have emphasized the interconnectedness of the family unit as they provide physical, emotional, and cognitive support in the home (Sander, Maestas, Sherer, Malec, Nakase-Richardson, 2012; Vangel, Rapport, Hanks, 2011; Redolfi et al., 2017). Thus, this research

project could be one of the first to consider the concept of ambiguous loss as it applies to a non-caretaker family member. Consequently, the significance of this study is to examine how participants who experience a TBI-P during childhood see ambiguous loss. This study is also unique since it seeks to explore how TBI-P adolescents view their family, self, and situation in light of ambiguous loss, possibly allowing for further exploration of how an abstract concept like ambiguous loss could result in tangible consequences of adolescents, including extensions into education. Finally, while there is plenty of research on TBIs, there is still a need for further research into how adolescents cope and how they show resilience in a TBI-P environment (Butera-Prinzi & Perlesz, 2004).

This study also extends previous research into the stress of family members who secondarily experience a traumatic injury. Researchers already know that caregiver stress is damaging to the family unit as the family must deal with the added stress and responsibilities that come along with caring for an injured person (Redolfi et al., 2017). Other studies have shown that the sudden changes experienced by the brain injury victim can lead to sometimes volatile disagreements between the injured party and family members (Ponsford, Olver, Ponsford, & Nelms, 2003; Wells, Dywan, & Dumas, 2005). Depending on the severity of the injury, researchers expect to see varying levels of family stress. Therefore, one assumption is if the caregiving spouse is under stress, the children in the home will also experience negative effects. This research project will investigate the influence of TBI-P on how adolescents may experience ambiguous loss.

### **Delimitations**

This study focuses on the concept of ambiguous loss and how, as it pertains to TBI-P, it takes shape for adolescents in their day to day lives. This study also focuses on the ways in

which adolescents construct definitions of their family, self, and situation as they experience an ambiguous loss. Finally, the study focuses on how the perception of ambiguous loss might result in tangible consequences in the lives of adolescents experiencing TBI-P. To be eligible for this study, participants needed to have a parent who experienced a moderate to severe traumatic brain injury while they were between 7 to 24 years old. Participants were not considered for this study if their parent experienced a moderate to severe brain injury while the adolescent lived at home and still lived at home for at least part of the recovery process. This study was completed during the summer and fall of 2021 in a large, metropolitan city in the southeastern United States. The study consisted of a five-person sample, all who experienced a TBI-P in their adolescence and childhood. While the study was originally planned to only include adolescents experiencing a current TBI-P, the study was widened to include pre-adolescent children and young adults up to the age of 25 who experienced a TBI-P event in their adolescence while living at home. The addition of young adults was made because young adults who went through a TBI-P experience could offer valuable insight into how their concept of ambiguous loss played out over the years following the injury. These young adults could also offer insight into how their definitions of family, self, and situation evolved over time and how their lives may have been altered due to the TBI-P.

### **Definitions of Significant Terms**

Several of the terms that appear in this dissertation study carry a variety of meanings and significant weight in the field. Accordingly, it is important to delineate their meaning as a way of clarifying and sharpening the focus of the study. As used within this particular study, these words will be defined in this way:

Ambiguous Loss- a loss of a person without death. Ambiguous loss can occur when someone is absent in mind but present in body, or absent in body and present in mind. For this study, ambiguous loss refers to a parent who is present in body but, through a moderate to severe traumatic brain injury, is absent in mind. For this study, when discussing ambiguous loss, the focus is on the inability of an adolescent to mourn or receive closure regarding their injured parent since they are still alive.

TBI-P- parental traumatic brain injury. These TBIs occur to a parent of an adolescent who is living in the home at the time of injury and at least partially during the recovery period.

TBI- a moderate to severe brain injury, excluding mild TBIs and concussions.

### **Summary**

This dissertation is focused on parental traumatic brain injuries and how they affect adolescents who experience the event while living at home. This research focuses on three major research questions:

Research Question 1: As it pertains to TBI-P, what is the influence of ambiguous loss when experienced during adolescence?

Research Question 2: When TBI-P is experienced in adolescence, how does the perception of ambiguous loss result in tangible consequences later in life?

Research Question 3: In what ways do adolescents experiencing ambiguous loss from TBI-P describe their family, self, and situation?

While the existing literature focuses heavily on primary family caregivers, there are fewer studies that focus on how adolescents process trauma from TBI-P. Consequently, this gap in the

literature is what this project intends to fill. Chapter two provides the review of the literature and will inform the design and implementation of this research study.

### **Organization of the Remaining Chapters**

The remaining chapters of this study are organized in the following manner. Chapter two covers a broad literature review centered on adolescent stress response, post-traumatic stress disorder (PTSD) in response to a traumatic event, family functioning after a traumatic event, and the concept of ambiguous loss. Chapter three discusses the research design and methodology of the study, which is a phenomenological case study design. Chapter four covers the results of the study, including thematic outcomes found in the data. Chapter five concludes the research project with a discussion of the results, conclusions of the study, and recommendations for future research.

## CHAPTER 2: REVIEW OF LITERATURE

Not isolated nor a rarity, TBIs are a widespread and significant health issue in the United States. In 2014, the last year data was available, approximately 2.87 million TBI cases were reported in the United States, which includes emergency room visits, inpatient hospitalizations, and deaths (Centers for Disease Control and Prevention, 2019b). While most of these TBIs were of mild severity, TBIs can cause long-term issues when they are moderate to severe in severity (Centers for Disease Control and Prevention, 2003). In the United States, it is estimated that approximately four-to-five million people live with a disability caused by a moderate to severe TBI (Centers for Disease Control and Prevention, 2014; Langlois, 2006). However, these data are not certain as there are inconsistencies in how medical professionals designate a TBI and whether they include multi-injury fatalities that could have other causes of death (Tiar & Dumas, 2015). While the CDC defines TBIs as “caused by a bump, blow, or jolt to the head that disrupts the normal function of the brain” (Centers for Disease Control and Prevention, 2019a, para. 2), the Traumatic Brain Injury Act of 1996 and amended in 2000, states that a TBI is, “[A]n acquired injury to the brain. Such a term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to trauma.”

As a TBI causes strain on the injured family member and the supporting family unit, research on the stress of caretaking in general is well documented in the literature (Leonardi, Giovannetti, Pagani, Raggi, & Sattin, 2012; Giovannetti, Leonardi, Pagani, Sattin, & Raggi, 2013; Tramonti et al., 2015). When compared to other traumatic events, TBIs create additional health concerns in five broad categories, including cognitive, behavioral, emotional, motor, and somatic symptoms (Walker & Pickett, 2007; Riggio & Wong, 2009). Not only do TBI survivors

have to work through physical or mental changes, but they must also concern themselves with other compounding symptoms related to their injury, including issues in regulating emotions and behavior which makes any recovery efforts that much more difficult. In addition to physical and psychological consequences, moderate to severe TBIs also have the potential to cause long-term financial strain on the family. In 2010, the indirect and direct medical costs of TBIs exceeded \$76 million dollars, placing further strain on caretakers and the whole family unit (Finklestein, Corso, & Miller, 2006; Coronado, McGuire, Faul, Sugerman, & Pearson, 2012). Specifically, when someone experiences a moderate to severe TBI, loss of income can quickly add additional stress to the family unit. From caretaking, changes in emotions or behaviors in the injured person, changes to sleep and work patterns in the injured person, changes in emotional responses of family members, and loss of income, moderate to severe TBIs tend to tax the entire family unit and result in losses that cannot be accounted for by quantitative studies alone.

Researchers have long understood that moderate to severe TBIs cause stress for both TBI survivors and their caregiving families and that these effects are normally long-term (Talking With Children About TBI, 2012; Shepherd-Banigan, 2018; Carlozzi et al., 2020). The knowledge-base surrounding TBIs has been well-covered in the existing literature and has focused on the brain-injured person and the primary caregiver, the psychological and physical challenges they face, how adolescents deal with stressful situations but not TBI-P in particular, and how other peripheral foci interact with TBIs (Perlesz, Kinsella, & Crowe, 2000; Kreutzer et al., 2009; Redolfi et al., 2017). Researchers have also long noted major concerns for TBI patients, including cognitive issues including the reduced ability to reason abstractly (National Institutes of Health, 1999) and psychosocial issues including agitation (Cunningham et al., 1999). However, TBIs range in severity from mild to severe and there are vast differences in how

TBI patients respond to TBI dependent upon the severity of the injury, the recovery time, and the strain placed on the family unit for caretaking (Degeneffe, 2001).

While some families might struggle with simply controlling the difficult behaviors that emerge post-injury (Rosenthal, 1989), other families deal with the loss of functional ability, or the ability of the injured person to tend their needs or their families' needs (Kieffer-Kristensen & Teasdale, 2011; Sieh, Meijer, & Visser-Meily, 2010a). No matter the struggle that families face, there is ample research that shows caregiving is an entire-family endeavor (Sander et al., 2012; Vangel et al., 2011). Thus, in addition to the injury, adolescents must also adjust their lives as the non-injured parent takes over caregiving responsibilities. Then, it is possible that the children are left with different post-injury relationships with both parents and how they view them in light of the TBI (Lezak, 1988; Armistead, Klein, and Forehand, 1995; Kieffer-Kristensen & Teasdale, 2011). Consequently, adolescents are left to consider their pre-injury lives and to continuously mourn, known as ambiguous loss, as they adjust to a continuous cycle of change in both their injured and non-injured parents. While some adolescents can show resiliency and receive some sort of closure, there is no existing study to show how prevalent this is. This type of mourning can last for days, months, or years and might never offer a sense of closure, placing what is believed to be an incredible strain on children during their formative years.

The existing literature has not comprehensively applied the idea of ambiguous loss to adolescents who experience a parental traumatic brain injury (TBI-P). In fact, there are many more research articles on primary caregivers' perception of stress but relatively very few articles on the effect of primary or secondary stress on children (Butera-Prinzi, 2004). The following literature review is broken down into multiple focus areas surrounding stress, post-traumatic stress disorder (PTSD), system/family effects of stress, and the concept of ambiguous loss. To

determine what has been written surrounding traumatic brain injuries and the family unit, this literature review will synthesize the common themes found among studies in this field and to sharpen the focus of the following chapters.

### **Theoretical and Conceptual Framework**

As this dissertation is focused on how adolescents and children experience ambiguous loss and the role of that loss in their lives, the logical starting assumption is that adolescents will experience stress at home due to their parent's TBI. Accordingly, the various frameworks found in the literature closely align to family stress and coping mechanisms used by family members to cope with a traumatic injury. As a result, the literature acknowledges stress as a major theme used for most of the theoretical frameworks discovered for this project. Under the overarching umbrella of stress theory, other theoretical frameworks branch off to sub-frameworks that exist under the initial scope of stress. The major theoretical framework used for this study is the ABCX Model developed by the founder of family stress theory, Reuben Hill (Weber, 2011). Hill (1958) offered crucial insight in his theoretical model's meaning, breaking down the model's elements into digestible parts:

A: The Crisis-Precipitating Event/Stressor: An event (crisis) that has no warning.

Families must respond to the crisis but their response is different from family-to-family, based on the accompanying hardships of the crisis.

B: The Family's Crisis-Meeting Resources: How well can the family unit avert a crisis or encourage it, all based on the family organization? These resources are determined by the integration and adaptability of the family unit.

C: The Definition the Family Makes of the Event: How families define the event or stressor determines their reaction to it. A negative view of the event will allow the family to be crisis-prone versus crisis-proof.

X: The Crisis: The individual roles of each family member are altered, along with the expectation of each member; changes include affection and emotional responses within the family unit.

Using a series of inputs and outputs, this model focuses on how dysfunction or positive family cohesion can affect the response to a crisis. Consequently, the 'x' factor in the model is what determines whether a family successfully exits the crisis or whether they deteriorate. Weber (2011), however, determined that the original model was too linear in its design and did not take into account the order of the model elements carefully enough. In turn, Degeneffe (2001) made note of McCubbin and Patterson's Double ABCX model of family stress theory, which posits that post-crisis variables are important when attempting to investigate familial crisis and the adaptability of some families over others (Patterson, 1988). In addition to post-crisis variables, Weber (2011) also added:

Additional life stressors and strains; psychological, intrafamilial, and social resources; changes in the family's definition; family coping strategies; and a range of outcomes, with family coping strategies being the Double ABCX Model's major contribution to stress theory.

To synthesize, the focus of the previously discussed stress models must not only center on the precipitating events and family structure leading to the stressful event, but must also take into account the many variables that make a family function successfully. These variables include: strong parental leadership of the non-injured parent, integration and adaptability capabilities of

the family, and the general positive worldview of the family unit (Hill, 1958). Without a focus on external factors that affect positive family functioning, researchers risk missing important data that could direct future research. As Hill (1958) noted, “successful experience with crisis tests and strengthens a family, but defeat in crisis is punitive on family structure and morale” (p. 147).

In alignment with this type of framework, similar frameworks have been used in the research of TBI-P that include a focus on the entire family unit and their ability to successfully navigate a devastating TBI, including a special emphasis on stress-coping behaviors. Researchers have repeatedly argued for updates to theoretical frameworks, including Perlesz, Kinsella, and Crowe (1996) and Turnbull and Turnbull (1991) argued for a theoretical framework that focused on the entire family unit. Other researchers agreed, stating that any theoretical framework of stress must be comprehensive in nature, assuming the positions and experiences of all involved family members, not just the primary caretaker (McCubbin & McCubbin, 1991; Godfrey, Knight, & Partridge, 1996). Kosciulek, McCubbin, and McCubbin (1993) also noted that any theoretical framework must include pre-existing stressors and their effects over time while Perlesz, Furlong, and McLachlan (1992) took a more hands-on approach, putting forward a theoretical framework that included a comprehensive understanding of the varied and logistical tasks families face after a TBI. In agreement with Perlesz et al. (1992), Kosciulek (1994a, 1994b) also argued for an analysis of how the family unit copes with the injury, not simply how the injured person copes with it. With a focus on the entire family unit and a purposeful concentration on how a family perceives a TBI-P, including dependent children, any future theoretical frameworks must take a holistic approach in determining how the family unit is affected by a TBI-P and what elements need to be in place to effectively determine how the construct of ambiguous loss determines the self-view and life outlook of adolescents

experiencing the event. In the following sections, a review of the literature assists in positioning this research study.

### **Literature Search Strategy**

The following sections outline the databases and keywords used for this literature review.

#### **Databases Used**

The literature review was conducted by accessing multiple databases through the UNC Charlotte library website. The search strategy included finding peer-reviewed journal articles, books, published but non-refereed articles, websites, and online periodicals written by specialists in the fields of trauma, traumatic brain injuries, trauma in adolescence, neurotrauma, and neuroscientists. The databases used for this dissertation included ProQuest Central, ERIC, PsycINFO, PsycARTICLE, and PubMed. Articles were also sourced from citations found in these databases, resulting in secondary searches to find the primary source.

#### **Keywords**

To begin my investigation into TBIs, I used a broad search of traumatic brain injuries. As expected, the initial search returned hundreds of thousands of results. Within these results, I noticed that the articles were focused on two major groups: adults and children. Since I was not interested in TBIs in children, I then narrowed my search to include only traumatic brain injuries in adults. This search tightened my results by half of the original returns on the initial search. However, these articles were spread across a vast range of articles focused on clinical neurotrauma, prevention of TBIs in older adults, and human brain mapping. I further pressed into the search by looking for traumatic brain injuries in adults, conducting searches with numerous keyword combinations, including traumatic injuries, traumatic brain injuries, TBI and family, parental traumatic brain injuries, parental acquired brain injury, coping, adolescent response to

trauma, adolescent caregiving, stress, adolescent response to stress, caregiving stress, and family caregiving stress. Specifically, in PubMed, I used the keyword combination of ‘child of impaired parents and brain injury and (stress)’. In ERIC/PsycInfo/Web of Science, I used the search keyword combination of ‘brain injury and parent\* and child\* and stress’. For articles that were not part of the UNC Charlotte Library collection, I requested their delivery, which is important since my topic is very narrow in scope. I also used federal reports to inform me on the scope and breadth of TBIs in the United States.

### **Literature Review**

The literature review covers research in the areas of stress, PTSD, family system effects, and ambiguous loss. Stress has been shown to cause negative outcomes when experienced during adolescence, especially considering how adolescents experience stress differently than adults. When adolescents experience a traumatic event, they can also show symptoms of PTSD. Consequently, family units are placed under greater stress after the traumatic event which can lead to parental tension and diverted attention from the adolescent family member. In totality, all of these elements can lead to the feeling of ambiguous loss.

### **Stress**

Researchers across the literature agree that childhood stress has long-term negative effects. However, there is no consensus as to the depth of those effects. At its core, stress can be defined as “any external perturbation to an organism's optimal homeostasis” (Dow, 2014). When a person responds to stress, it could come in the form of coping in which there is a continuous adjustment in both cognitive processes and behavior in order to account for the stress, either through focusing on the cause of the stress or focusing on their emotional response to it (Verhaeghe et al., 2005). First researched during World War I, researchers used a

phenomenological approach to connect TBIs with the inability of some soldiers to think abstractly and to return to everyday activities, bringing much needed attention to a common injury of war (Goldstein, 1942). Following this publication and pushing TBI research towards the injury's effect on others and stress, London (1967) asserted that a TBI-P event could serve as a weakening force to the family unit and could create opportunity for discord to erode familial relationships. Consequently, in the late 1960's and early 1970's, researchers studied soldiers who suffered TBIs from World War II and found that most of their complaints centered around issues of irritability, depression, and reduction in confidence (Russell, 1971; Newcombe, 1969; Lishman, 1968).

Researchers have focused on TBIs in the literature but have spent far less time exploring the influence of moderate to severe TBI-P on adolescents who must live with a psychologically and physically-changed parent. To begin, at the core of childhood stress as it relates to TBI-P, research has shown that adolescents who experienced a parent with a chronic medical condition reported more indicators of chronic stress and a reduced quality of life when compared to adolescents with healthy parents (Bruin, Sieh, Zijlstra, & Meijer, 2018). In this study, the researchers used a self-reporting questionnaire to gauge how stress impacts adolescents with a chronically-ill parent. Other researchers found that childhood stress can heavily affect adolescents' quality of life, including psychological and physical health problems over time (Hocking & Lochman, 2005; Pedersen & Revenson, 2005; Sieh, Visser-Meily, Oort, & Meijer, 2014). Dewald, Meijer, Oort, Kerkhof, and Bögels (2014) agree, suggesting that pre-existing stress might negatively alter behaviors in succeeding circumstances, bringing stress into an expanding loop of behavioral modifications in adolescents. In relation to TBI-P, adolescents are

at a higher risk of developing stress as a reaction to the injury as compared to adolescents who do not experience a traumatic parental injury (World Health Organization, 1992).

As stress relates to TBI-P, Kobak (1999) found that adolescents, whose family members or parents experience a TBI-P, experience acute distress and other strong emotions which threaten their psychological well-being. A slew of researchers agree, positing that stress related to a TBI-P is high enough to warrant psychological intervention for children in the home (Machamer, Temkin, & Dikmen, 2002; Wade et al. 2002; Hawley, Ward, Magnay, & Long, 2003; Klonoff, 2014; DeTanti, Zampolini, & Pregno, 2015). In turn, Butera-Prinz and colleagues (2004) acknowledged that children living with a father who experienced a TBI were at risk of developing emotional difficulties, including “a complexity of feelings associated with the trauma and multiple losses, including profound grief, social isolation and fear of family disintegration and violence” (p. 83). The researchers used secondary data to validate their findings, including observations, self-reporting, and parental reporting questionnaires (Butera-Prinz et al., 2004). However, it is not simply the single TBI event that puts adolescents at risk of emotional difficulties, but the idea of recurring stress tied to the injury. For example, researchers note that children experiencing persistent stress over their childhood years is not simply the response to a traumatic event, but rather a result of the culmination of their lived experiences (Weber, 2011; Bruin et al., 2018). Thus, if the experience of the TBI-P is conjoined with other factors in a particular family structure, such as family dysfunction or parental depression, there is the possibility of greater variance in the TBI-P experience.

### **Stress Differences in Adolescents Compared to Adults**

Stress can be longitudinal in effect, causing family members of TBI patients to score abnormally high on stress assessments up to 15 years after the incident, with the highest level of

stress focused on caregiving burden during the remaining lifespan of the injured person and the personal burden and responsibility of the family caregivers (Minnes, Graffi, Nolte, Carlson, & Harrick, 2000). In cases of moderate to severe TBIs, family stress is experienced over time and offers no end point or downtime. For adolescents, stress is a considerably different experience when compared to stress experienced as an adult. Researchers have claimed that because stress is tied to event-specific incidents and not generalized as adults might experience stress, there is an increased risk that adolescents will have longer-term consequences related to stress (Sanchez, Fristad, Weller, Weller, & Moye, 1994; Butera-Prinzi & Perlesz, 2004). In addition to this additional stress, adolescents have minimal access to supports needed to deal with the strain of TBI-P (Visser-Meily et al., 2005; Webster & Daisley, 2007; Klonoff, 2014) and have no working skills or supports to navigate a TBI-P (Kieffer-Kristensen & Johansen, 2013). Since adolescents process stress differently than adults, there is an additional strain when the relationship with the injured parent is negatively impacted, which serves as a catalyst for long-term stress in the day-to-day lives of adolescents (Kieffer-Kristensen & Johansen, 2013).

As the relationship between the brain-injured parent and adolescent weakens, the output of adolescents can move towards more negative feelings, emotions, or actions. One consistent emotion found in the existing literature is anger. However, some researchers have found that the anger is not necessarily associated with the injured parent, but directed at the brain injury itself and a lack of understanding from others, stemming from a feeling of isolation (Kieffer-Kristensen & Johansen, 2013). Other researchers disagree, noting that anger is often pointed towards the injured parent as they behave embarrassingly post-injury or because adolescents blame their injured parent for disrupting their lives (Hardgrove, 1991; Sachs, 1991; Kieffer-Kristensen & Teasdale, 2011). Regardless of whether the anger is directed at the situation or the

parent, the emotional toll of living with a brain-injured parent can create a higher risk of negative emotional, social, and educational outcomes with researchers showing that 90% of adolescents in their study experienced a negative behavioral change that was not present pre-injury (Visser-Meily et al., 2005; Sieh et al., 2010b; Kieffer-Kristensen et al., 2011; Kieffer-Kristensen & Johansen, 2013; Kieffer-Kristensen et al., 2013).

To this point, some researchers have found that adolescents reported feeling depressed (Visser-Meily et al., 2005; Kieffer-Kristensen & Johansen, 2013), acted out aggressively according to their parents' survey responses (Pessar et al., 1993), experienced relational problems such as withdrawing from social situations based on self-and-parental reporting mechanisms (Butera-Prinzi & Perlesz, 2004; Pessar et al., 1993) or performed poorly in school (Urbach & Culbert, 1991; Pessar et al., 1993). Summatively, adolescents who live with a head-injured parent have higher risks of developing emotional and behavioral problems (Lezak, 1978; Urbach & Culbert, 1991; Pessar et al., 1993, Visser et al., 2005) and are more prone to anxiety, sleeping issues, eating disorders, withdrawal from others, depressive symptoms, and aggression (Butera-Prinzi & Perlesz, 2004). As a result, many adolescents' stress related to the TBI-P event led to further negative concerns that manifest as lower academic self-esteem and a reduced happiness and over quality of life (Bruin et al., 2018). Related to lower academic self-esteem, adolescents might experience feelings of shame or resentment towards their situation, and historically have expressed their feelings through misbehavior at school (Urbach et al., 1994). Other researchers have cumulatively agreed, noting that reactionary stress related to an uncontrollable situation, like a TBI-P, is often shown through emotional outbursts or behavioral concerns (Kieffer-Kristensen et al., 2011; Kieffer-Kristensen & Johansen, 2013; Kieffer-Kristensen et al., 2013).

## **Adolescent Response to Stress**

While adults might experience stress caused by day-to-day stressors, researchers believe that children are different and experience their highest stress when it is caused by traumatic events. When such events occur, adolescents respond in a variety of ways, including feelings of depression, anxiety, and poor educational performance (Butera-Prinzi & Perlesz, 2004; Kieffer-Kristensen et al., 2013; Tiar & Dumas, 2015). Other researchers have suggested that isolation from others and avoidance of possible stress-inducing situations have manifested in some adolescents in a TBI-P event (Urbach & Culbert, 1991; Pessar et al., 1993). In one study, researchers found that 63% of adolescents experiencing a TBI-P event “showed signs of emotional distress and impairments” (Redolfi et al., 2017, p. 1057) in areas like sadness, behavior problems, and social isolation, which are in alignment with previous studies (Pessar et al., 1993; Uysal et al., 1998; Visser-Meily et al., 2005; Butera-Prinzi & Perlesz, 2004). Redolfi and colleagues (2017) also found that both the injured and uninjured parent often underestimate the effect the injury has on their children. On the meta-analysis level, researchers have consistently shown that adolescents whose parent has a chronic medical condition, such as a TBI, show more emotional problems than adolescents with healthy parents (Sieh et al., 2010a; Huizinga et al., 2005; Sieh, Visser-Meily, & Meijer, 2013). Aligned with previous research, a chronically ill parent suffering from a moderate to severe TBI has the potential to cause additional stress, increased risk for negative behavior, and emotional issues in adolescents (Sieh et al., 2013; Houck, Rodrigue, & Lobato, 2007; Huizinga et al., 2005; Verhaeghe et al., 2005).

## **Stress Coping**

Operationalized, coping is how people think or act in response to an external stressor and can affect how they navigate the stressful event (Lazarus & Folkman, 1992). When adolescents

are faced with a traumatic event in their lives, they implement coping mechanisms similar to how adults cope. Across studies, researchers have posited that adolescents respond to stress by either focusing the cause of it or by focusing on their emotional response to it (Verhaeghe et al., 2005). In one study, researchers found that there were five major coping strategies used by adolescents in a TBI-P environment, including distracting themselves from their reality, helping others as means to avoid thoughts about their own situation, independence from others, backing out of overwhelming situations which could trigger feelings of anxiety, and remaining positive through their mindset (Kieffer-Kristensen & Johansen, 2013a). Researchers have also found that when adolescents focus on the problem or situation, they exhibit lower less “internalizing and externalizing problem behavior...but higher levels for disengagement and emotion-focused coping” (Bruin et al., 2018, p. 1402).

### **Post-Traumatic Stress Disorder**

Another major issue in the existing literature, post-traumatic stress disorder (PTSD), shares commonalities with the aforementioned issues of emotional and psychological well-being of adolescents. Researchers believe that adolescents are capable of self-reporting their symptoms of PTSD and that these reports should be considered valid when self-reported (Kieffer-Kristensen et al., 2011; Yule, 2001). While there are different variations on what constitutes a traumatic experience, most experts agree that children can experience trauma through the death of a loved one or through a serious injury (Diagnostic and Statistical Manual of Mental Disorders: DSM-5, 2013). Of special interest, researchers have also found that parental injuries can be exceptionally traumatizing for adolescents (Leclere & Kowalewski, 1994) and that adolescents might be at a higher risk for PTSD than the general population when being forced to deal with a parental injury (Kieffer-Kristensen et al., 2011; Kieffer-Kristensen et al., 2013).

Comparatively, researchers are well aware that stress plays a significant role in determining how an adolescent enjoys or dislikes their life, how well they function psychologically, and whether they carry long-term health issues from their childhood to adulthood (Hocking & Lochman, 2005; Pedersen & Revenson, 2005; Sieh et al., 2014). Pynoos (1992) argued that when an adolescent experiences a TBI-P, their lives and daily routines are changed, resulting in secondary stressors that increase their likelihood of experiencing PTSD symptoms. Leclere & Kowalewski (1994) noted that when adolescents see the actual traumatic event or learn about it after the fact, they are particularly more vulnerable to exhibiting PTSD symptoms. Kieffer-Kristensen and colleagues (2011) went a step further, arguing that adolescents who experience a TBI-P are likely to experience the adverse effects of a PTSD episode, including a substantial negative shift in family relations. Tied together, the literature points to the risk of PTSD in the lives of adolescents who experience a TBI-P and the numerous negative effects that follow such a traumatic event.

More importantly, the literature shows that a traumatic TBI-P experience has long-lasting impacts on the adolescent, following them into adulthood in most cases (Eth & Pynoos, 1985). In fact, Kieffer-Kristensen et al. (2011) argue that the symptoms exhibited by adolescents experiencing a TBI-P “may thus be particularly vulnerable to the trauma-specific symptoms, such as those measured by scales for post-traumatic stress, rather than to generalized anxiety and depression” (p. 753). In agreement, multiple researchers found that PTSD symptoms are common in TBI-P adolescents and that experiencing a traumatic event puts them at greater risk for emotional and behavioral issues well into adulthood (Huizinga et al., 2003; Edwards et al., 2008). Other researchers found PTSD symptoms at a ratio of approximately 5-to-1 when comparing TBI-P adolescents to adolescents with healthy parents (Kieffer-Kristensen et al.,

2011). Consequently, the existing literature has a heavy emphasis on PTSD and stress theories, which are foundational in the investigation of how adolescents process a TBI-P event.

### **PTSD Stages and Processes**

PTSD is well-covered in the existing literature and can be applied to TBI-P adolescents. Researchers created multiple models to describe a general process of PTSD and how the traumatic event progresses from the initial event through post-event (Lezak, 1986; Curtiss, Klemz, & Vanderploeg, 2000; Degeneffe, 2001; Verhaeghe et al., 2005). To visualize the process, Veraeghe and colleagues (2005) offered a general progression of PTSD in relation to TBI:

During the opening phase, the initial shock is lived through. Medical stabilization and damage minimization are absolute priorities. The family grows closer together and directs all its energy towards the injured person. Phase two involves emotional relief, denial and unrealistic expectations with regard to the evolution of the injury. It is likely that the euphoria of survival minimalizes problems and prolongs the expectation of subsequent full recovery. The ensuing third phase involves bewilderment, anxiety, dejection, depression, feelings of guilt, despair and the feeling of imprisonment. Some families eventually evolve into a final phase of sorrow and mourning, role reorganization and role redistribution, the aim of which is to promote as much as possible the patient's recovery and integration. Not all families pass through every phase or display every characteristic of a particular phase. (p. 1007)

In this progression, the family can be thought of as contracting (coming together) and negatively expanding or drifting apart. In the first phase, the contracting of the family unit is highlighted as most families come together to fight through the initial injury and prognosis. In the second

phase, although the family might still hold hope that a full recovery to a pre-injury normal life is within reach, there is a possibility that the injury will progress and hold negative outcomes for the patient; this can create friction between family members, some of whom might disagree on the outcome prognosis. In the final phase, families readjust to their realities, including a move towards mourning a still-living family member, known as ambiguous loss, which is a major part of this dissertation. Thus, while researchers know the general process of how PTSD might unfold, they are also aware that each family moves through some of the phases at different speeds, if at all. This research aligns with Butera-Prinzi and Perlesz (2004) who noted that adolescents experience trauma in complex ways, building from Monahon (1993) who acknowledged that trauma in adolescence is unique and never fully explainable by any singular model.

PTSD follows a general phased flow of events or feelings. Concurrently, a moderate to severe TBI follows a phased flow of its own that intersects with the PTSD model. Researchers have visualized TBI recovery as consisting of two phases (Ponsford, Olver, Ponsford, & Nelms, 2003). In the first phase, called the acute phase, the first few months post-injury consists of rapid recovery and then a progressive return to a new sense of normal. With the previously mentioned PTSD model, phase one of the TBI model would interact heavily with the initial and second phases of that model. In the second phase of the TBI model, called the chronic phase, the worrisome feelings of ambiguous loss, a physically present parent who is psychologically unavailable, and a feeling of neglect can increase feelings of stress in family members (Boss & Couden, 2002). The second phase of the TBI model intersects with the third phase of the PTSD model. Put differently, a TBI-P that results in PTSD can cause major problems for adolescents, especially when the physical and mental consequences of a moderate to severe TBI are not felt

immediately but occur over time (Kieffer-Kristensen et al., 2013; Butera-Prinzi & Perlesz, 2004). The intersections of these two models highlight researchers' belief that PTSD caused by TBI can create a convoluted system of emotional and behavioral concerns, which are often not apparent at the time of injury and can cause distress in adolescents (Vaishnavi, Rao, & Fann, 2009; Butera-Prinzi & Perlesz, 2004).

### **PTSD and TBI-P**

Compared to other types of parental traumatic injuries, such as stroke or cancer, researchers acknowledge additional stressors increase the risk of adolescent PTSD amongst TBI-P family members (Pynoos, 1992). Building from this base, Kieffer-Kristensen and colleagues (2011) divide these stressors into three categories, including type one (reduced parental attention post-injury), type two (parental marriage strain due to the injury), and type three (daily life changes). In the first category, adolescents feel as if their non-injured parent's attention is being pulled away from them and towards the injured parent (Kieffer-Kristensen & Teasdale, 2011; Ducharme, Spencer, Davison, & Rushford, 2002; Sieh et al., 2010; Redolfi et al., 2017) which has been shown in other studies (Pessar et al., 1993; Uysal et al., 1998). In the second category, parents experience more strain than usual and the marital relationship creates reduced levels of felt bond and happiness (Gosling & Oddy, 1999; Kreutzer, Marwitz, Hsu, Williams, & Riddick, 2007). As the relationships between parents weakens, adolescents are more likely to feel less stable or safe in their role as children (Kieffer-Kristensen et al., 2011). In the third category, the outcome of the injury can lead to changes in daily routines which could add stress to an already-stressed child. As a result, researchers have noted higher levels of PTSD symptoms for adolescents experiencing TBI-P when compared to adolescents experiencing a different type of

chronic medical condition (Kieffer-Kristensen et al., 2013; Kieffer-Kristensen et al., 2011; Butera-Prinzi & Perlesz, 2004; Monahan, 1993).

Not all researchers agree that TBI-P adolescents are at a higher risk of developing or exhibiting PTSD symptoms, with some researchers noting that the outcome of the injury on their lives is based on the adolescent's resilience. These findings contradict the number of studies that correlate TBI-P and PTSD symptoms, but are worth exploring here. Some researchers believe that although a TBI-P can be a negative event in the life of an adolescent, some adolescents rise above their environments to better outcomes (Anthony & Cohler, 1987; Kaufman, Grunebaum, Cohler, & Gamer, 1979; Rutter, 1985). In their findings, previous researchers acknowledge that protective factors determine either positive or negative outcomes for adolescents (Rutter, 1985). Protective factors include a positive home life both pre-and-post injury, adolescent access to support systems and a positive non-injured parent at home, and support and access to positive influences outside the home (Haggerty, Sherrod, Garmezy, & Rutter, 1996; Cuff & Pietsch, 1997). A partial cause for this tension in the literature could be that a TBI-P causes exposure to trauma that might not be as obvious as other sorts of trauma, such as witnessing a fatal car accident or watching a parent pass away. Since a moderate to severe TBI-P is a longitudinal event, the trauma is cumulative and occurs many times over a set period of time (Kieffer-Kristensen & Johansen, 2013). Thus, some divergent studies that report no change in PTSD risk might not be longitudinal enough to be valid.

Experiencing PTSD with a TBI-P enhances the possibility that adolescents will also experience the loss of relationships with both the injured and non-injured parent, a higher risk of parental separation, further parental illness connected to the injury, or the eventual death of the injured parent (Leclere & Kowalewsk, 1994; Copeland, Keeler, Angold, & Costello, 2010).

Previous research indicates that adolescents are extremely vulnerable to their parents' reactions to the traumatic event and thus, relationships between parent and child can become strained based on those reactions (Cohen, Kelleher, & Mannarino, 2008; Cohen & Scheeringa, 2009). If adolescent response to TBI-P is based on the many variables previously discussed, the family system then becomes an integral part of the adolescent experience post-injury and might determine how severe the family reacts to the injury. Trauma has been found to be experienced differently by adolescents, a result borne out across the literature (Butera-Prinzi & Perlesz, 2004; Thastum, Johansen, Gubba, Olesen, & Romer, 2008).

Interestingly, while other kinds of trauma and their effects on adolescents have been studied, "the sometimes profound losses and individual suffering of the children of parents with a head injury have been neglected in the literature" (Butera-Prinzi & Perlesz, 2004, p. 83). For researchers who have studied TBI-P and adolescent response, high enough levels of PTSD were found to warrant professional interventions with a specific concern about long-term outcomes for these adolescents (Pynoos et al., 2009; Kieffer-Kristensen et al., 2011). Consequently, while there is a need to focus on the adolescent experiencing a TBI-P event, there is a concurrent and arguably more pressing need to include the family unit in the research. If PTSD plays a role in the post-injury world of the adolescent, the family surrounding the adolescent would logically experience some sort of trauma, too. In a TBI-P environment, the effect is threefold on the family unit and affects the injured person, the healthy parent, and the children in the home. These effects, known as system effects, are explored in the following section as they pertain to TBI-P.

### **System Effects**

While the aforementioned research focuses on stress and PTSD as they pertain to adolescents experiencing a TBI-P, the entire family unit is changed and affected by the injury as

the injury causes negative changes to the cognitive processes, behavioral norms, and personality of the injured parent (Keiffer-Kristensen & Teasdale, 2012). While other researchers believe that there is no universal sense of stress in TBI-P situations (Camplair, Kreutzer, & Doherty, 1990; Adams, 1996), most researchers have found that TBI-P causes considerable strain on families (Kieffer-Kristensen et al. 2011; Kreutzer et al., 2009; Perlesz et al., 2000) and that the unexpected nature of TBI-P can serve as a catalyst for long-term, negative effects to the family unit (Tedeschi & Calhoun, 1995). While the literature has been mostly concerned with a spousal or parental response to trauma, the adolescent response is important to consider as their recovery from exposure to the event is based on the family unit's response (Gosling & Oddy, 1999; Kreutzer, Marwitz, Hsu, Williams, & Riddick, 2007). A critical view of the existing literature is that it compartmentalizes family members by treating them as separate entities while they should view the family as a whole (Sieh, Visser-Meily, Oort, & Meijer, 2012; Sieh et al., 2010; Korneluk & Lee, 1998) and that stressors that affect the parents might also affect the adolescents, known as a cluster effect (Sieh et al., 2012; Snijders & Bosker, 1999). However, without a view of the component parts of a family, a more wholesome picture of the family's response to the TBI-P would not be as thorough.

As a TBI-P affects multiple vested parties, such as the injured person and their immediate family, it is important to acknowledge the system effects that stretch over the entire family unit. Researchers believe that adolescents experiencing a TBI-P show general signs of PTSD (Kieffer-Kristensen & Teasdale, 2011; Kieffer-Kristensen) and have acknowledged that the effects on the family unit originate through personality changes and emotional challenges in the injured person (Ponsford et al., 2003; Wells et al., 2005). One study focused on the relatives of TBI survivors and reported more than 50% of them experienced significant stress based on the declining

behavioral tendencies of the injured person and about their prospects of a secure future (Cunningham et al., 1999; Degeneffe, 2001). While some family tension might decrease in the second year post-injury, (Oddy & Humphrey, 1980), the overwhelming sense of responsibility by family members can lead to multiple negative consequences for the family as a whole (Karpman, Wolfe, & Vargo, 1985), including marital distress (Moore, Stambrook, & Peters, 1993; Peters et al., 1990) and disrupted parenting (Gervasio & Kreutzer, 1997).

The literature indicated an issue of parenting changes and associated negative outcomes on children whose family members have experienced a TBI-P. Many adolescents deal with a shifting family dynamic when their non-injured parent steps into a caregiving role. Researchers have found that adolescents must deal with the non-death loss of their injured parent while also losing their functioning parent to an overwhelming sense of responsibility and stress (Butera-Prinzi et al., 2004). Other researchers agree, affirming that caregiving often occurs in conjunction with an overwhelming sense of responsibility that then interacts with negative feelings of grief, including denial and frustration about the situation (Mathis, 1984). In such a situation, the non-injured parent is responsible for keeping the family unit cohesive and caring for their spouse, who might be a completely different person post-injury (Degeneffe, 2001).

### **Disrupted Parenting**

The first and perhaps most important system effect after a TBI-P is disrupted parenting, first introduced by Armistead and colleagues (1995). Disrupted parenting refers to the reduced role of both the injured and non-injured parent in caring for and nurturing their child after the TBI-P event, which is a result of stress on the marital relationship, stress on the individual parents as they process the injury, and depressive symptoms in one or both parents (Kieffer-Kristensen et al., 2013). With TBI-P, less attention might be paid to children (Pessar et al., 1993;

Uysal et al., 1998; Keiffer Kristensen & Teasdale, 2011) as the non-injured spouse is forced to focus on the injured spouse, reducing parent-child interactions (Armistead et al., 1995).

Disrupted parenting is detrimental to both the non-injured parent and child, causing there to be less attention paid to the adolescent and more stress between parents, beginning a cyclical back-and-forth that adds more stress each cycle (Rolland, 1997). Researchers are aware that adolescents experience major stress as parental attention decreases (Klonoff, 2014; Dix & Meunier, 2009; Kieffer-Kristensen et al., 2011; Uysal et al., 1998). As families are tasked with becoming primary caregivers post-injury, they are almost guaranteed to create new family roles and expectations to accommodate the injured parent and to create a new sense of cohesion amongst family members (Verhaeghe et al., 2005; Florian, Katz, & Laman, 1989; De Marle & Le Roux, 2001). While it is expected that the injured parent will experience stress and negative psychological change and a reduced level of interaction with their child, multiple researchers found that the level of stress experienced by the healthy parent can directly impact the care and nurturing the adolescent receives post-injury (Visser, Huizinga, Hoekstra, van der Graaf, & Hoekstra-Weebers, 2006; Armistead et al., 1995).

If both parents are unavailable to support an adolescent, a cyclical process begins whereas the adolescent seeks care and nurture from both parents who, in effect, send the adolescent back to the other parent. This is detrimental to adolescents, especially when the healthy parent must also deal with anxiety and mood changes in the injured parent (Kruetzer et al., 1994; Wallace et al., 1998; Marsh, Kersel, Havill, & Sleight, 1998; Ponsford et al., 2003; Verhaeghe et al., 2005).

Ideally, the healthy parent becomes the protector of the adolescent and ensures the adolescent has limited interaction with the injured parent. Alternatively, the non-injured parent might serve in a parallel parenting style where they norm minimal communication, engage in higher levels of

conflict, and/or disengage emotionally with the adolescent in a form of misplaced anger (Hetherington, Stanley-Hagan, & Anderson, 1989).

The literature has long been aware that adolescents in a TBI-P environment are at risk of being mistreated by both parents, albeit through intentional or unintentional means (Lezak, 1978). As a result of these claims, other researchers posited that over 90% of their parental participants reported their adolescent had experienced a negative behavioral change since the injury occurred, including acting out and emotional problems (Pessar et al., 1993). Not any fault of their own, adolescents are forced to respond to disrupted parenting whereas parents:

...May become detached and disinterested, preoccupied and self-absorbed. moody and irritable, volatile and explosive, confused and forgetful. or strange and delusional.

According to age and other circumstances, the child may be challenged by a disruption of primary bonding, a loss of stable object relations, a loss of affectional ties, the alteration of a major identification figure, or a confrontation to reality testing. (Urbach & Culbert, 1991, p. 27)

Consequently, adolescents in other studies noted their non-injured parent was over-stressed (Butera-Prinzi, 2004), that they had to compete with the injured parent for attention (Verhaege et al., 2005), that they felt like they mattered less than the injured parent (Carson, 1993), that they had more caretaking and household responsibilities than they did pre-injury (Degeneffe, 2001; Wesolowski & Zencius, 1994), that they experienced high-levels of grief and anxiety towards both the injury and their changed home life (Degeneffe, 2001), and that shifts in familiar routines were adding stress to their lives (Urbach & Culbert, 1991). At the core of these issues is the idea of disrupted parenting, whereas a parent is unable to perform emotionally or cognitively at the same level as pre-injury.

For the injured parent, disrupted parenting will more than likely be more severe and pronounced compared to the non-injured parent. After a TBI, the injured parent might experience cognitive or behavioral challenges (Lezak, 1988; Armistead et al., 1995; Kieffer-Kristensen & Teasdale, 2011; Ponsford et al., 2003; Wells, Dywan, & Dumas, 2005), be unable to ensure their adolescent's needs are attended to (Kieffer-Kristensen & Teasdale, 2011; Ducharme, Spencer, Davison, & Rushford, 2002; Pessar et al., 1993; Sieh et al., 2010), or exhibit a sharp decrease in attention towards the adolescent (Klonoff, 2014; Armistead et al., 1995; Dix & Meunier, 2005; Kieffer-Kristensen et al., 2011; Uysal et al., 1998). To compound these issues, parents must also navigate relational issues between themselves which also affects the adolescent, including marriage problems, affection and cohesion concerns, a lack of communication, and a decreased satisfaction in relationships with each other (Redolfi et al., 2017; Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011; Williams & Wood, 2013; Peters et al., 1992; Ponsford et al., 2003). Often, the injured parent cannot fulfill their day-to-day parental responsibilities nor are they capable of showing affection as they might have pre-injury (Urbach & Culbert, 1991; Pessar et al., 1993; Uysal et al., 1998; Butera-Prinzi & Perlesz, 2004). However, although less than the injured parent, the healthy parent will also experience disrupted parenting and struggle with balancing the demands of an injured spouse and an adolescent in need of attention.

### **Parental Depression and Psychological Responses**

In relation to disrupted parenting, the psychological responses to trauma in both parents deserves scrutiny here. Researchers have shown that parents who exhibit symptoms of depression negatively influence adolescents and serve to reinforce negative psychosocial outcomes (Dominik, Visser-Meily, & Meijer, 2013). In this particular study, researchers used self-reporting inventories and included parents with chronic medical conditions along with a

control group of healthy parents. For the injured parent, psychiatric symptoms include changes to personality, inability to control behavior, uncontrollable emotional responses, irritability, rapid mood swings, apathy and cognitive deficiencies (Urbach et al., 1994; Lezak, 1978; Prigatano, 1987; Lewis, 1991; Anthony, 1974). For the non-injured parent, some researchers have found anxiety and depression six years after the TBI (Linn, Allen, & Wilier 1994; Perlesz et al., 1999). Other researchers confirmed these findings, even positing that there was no reduction in these symptoms after seven years (Ponsford & Schonberger, 2010; Oddy, Coughlan, Tyerman, & Jenkins, 1985; Teasdale & Engberg, 2005b). Further research in this area has found such responses to be based on less marital satisfaction and greater marital conflict (Matiz, 1990; Kieffer-Kristensen et al., 2013; Visser-Meily et al., 2005). When parents are depressed in a TBI-P situation, that stress is often associated with the adolescent's stress, whereas the adolescent has behavioral outbursts which further stress the parents (Goodman et al., 2011; Langrock et al., 2002; Adrian & Hammen, 1993; Goodman & Gotlib, 1999; Pederson & Revenson, 2005).

### **Family Stress**

While the preceding sections dealt mostly with parental stress, the entire family unit can experience negative effects when experiencing a TBI-P. Panting and Merry (1970) noticed that many of the caregivers in their TBI studies reported symptoms of stress. Seminal works were then carried out on TBI stress and were first written in longitudinal studies by the Glasgow group of researchers (Brooks, 1991; Brooks et al., 1986; Brooks et al., 1987; Livingston, Brooks, and Bond, 1985a, 1985b; McKinlay et al., 1981) who noted that the more severe the head injury, the greater the psychological challenges and anxiety in family members. Other researchers have found that stress related to TBI does not reduce over time, which differentiates the stress from this type of caregiving to others (Douglas & Spellacy, 1996; Kreutzer et al., 1992; Panting &

Merry, 1970; Romano, 1974; Walker, 1972). Acknowledging the complexity of stress responses, researchers found that although the injured parents' psychosocial recovery levels off around six months post-injury, family members experience continuously rising stress levels (Oddy et al., 1978; McKinlay et al., 1981; Brooks & McKinlay, 1983).

The terms family stress and family burden might be used interchangeably as both refer to how family members cope with stress and both terms are grounded in British studies focused on general psychiatric patients and relatives (Grad & Sainsbury, 1963; Brooks, 1991; McKinlay et al., 1981; Brooks & McKinlay, 1983; Brooks, 1984; Urbach & Culbert, 1991). While family members who can positively respond to stress have better outcomes (Livingston 1987, Florian et al., 1989, Laughlin & McCarey 1993, Pelletier & Alfano 2000, Sander et al., 2002), the focus of their coping makes a difference. In a review of the literature, Verhaeghe and colleagues (2005) found that families with "problem-oriented coping skills appear to be more effective (in navigating a TBI-P) than emotion-oriented coping skills" (p. 1008) and that "young families with little social support, financial, psychiatric and/or medical problems are the most vulnerable" (p. 1004). Coping with traumatic brain injury can be described in phases.

When a family unit is under extra stress, most families respond negatively with many of them exhibiting signs of marital distress and less enjoyment of parenting activities while the injured parent often changes from a contributing member of the family to a physically and cognitively necessitous person (Uysal et al., 1998).

Across the literature, researchers have long been aware that any negative changes in the injured person's psychological, cognitive, or behavioral norms resulted in excessive stress in the family unit (Brooks, 1984; Fahyt, Irving, & Millac, 1967; Lezak, 1988; Rosenbaum & Nagenson, 1976; Weddell et al., 1980) and especially, the children (Willer, Allen, Liss, & Zicht,

1991; Lezak, 1978; Lezak, 1988). For children, TBI-P can cause many issues and lead to negative outcomes such as withdrawal (Lezak, 1978; Lezak, 1988), acting out behaviors (Pessar et al., 1993), and depression and anxiety (Livingston et al., 1985a; Livingston et al., 1985b). Coupled with the constant worries of the primary caregiving-parent, exceptional levels of anxiety, irritability, general unhealthy family relationships, resentment, and grief have all been noted in the literature (Kreutzer, Gervasio, & Camplair, 1994; Livingston et al., 1985; Oddy et al., 1978; Mauss-Clum & Ryan, 1981). Some researchers have found divorce rates as high as 50% within a decade of the trauma occurring (Panting & Merry 1970; Walker 1972; Thomsen 1984).

### **Family as Victim**

Family stress is expected during and after a TBI event, but some researchers consider the family to play a dual role: a resource to the injured person and a victim of those circumstances (Redolfi et al., 2017; Sander, Maestas, Sherer, Malec, & Nakase-Richardson, 2012; Vangel Jr., Rapport, & Hanks, 2011; DeTanti, Zampolini, & Pregno, 2015; Klonoff, 2014). The view of family as victim includes the means in which a family must, at times, uproot their lives to serve and protect the injured parent. As families rework their version of a normal life post-injury, they often fail to settle on that definition and are once again victimized (Verhaege et al., 2005; Cope & Wolfan, 1994). TBIs create stress and cause family dysfunction, which leads to conflict and more stress. As the cycle begins, it can be difficult for families to escape. As families remain unsettled after the injury, they make constant adjustments to their schedules, routines, and interactions with the injured parent, thus they are less likely to create a sense of familial cohesion and they remain stuck in a negative post-injury phase (Leaf, 1993).

As families struggle to adjust, researchers have noted that parents who become depressed about their life circumstances pass on their negativity to their children, who react in negative ways such as acting out behaviors (Urbach et al., 1994; Sieh et al., 2012). Other researchers (Ireland & Pakenham, 2010) found that the gradual nature of a traumatic health problem that does not result in death, sees its effects felt over many years, heavily contributing to the inability for adolescents to accept their new realities, which also affects the family unit. Interestingly, researchers have found that the severity of chronic medical conditions does not affect adolescents as much as the adolescent's perception of how stressful their lives have become (Korneluk & Lee, 1998; Verhaeghe et al., 2005; Visser-Meily et al., 2005). However, it is important to note that, due to the variability in parental illness and how chronic medical conditions and TBIs are classified, there is still relatively minimal research on how these events impact children; more research is needed in this area (Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006).

### **Adolescent Response to System Changes**

As families struggle to reconcile their old and new lives, children are left to process their feelings often without the support of other family members who may be focused on caregiving. Researchers acknowledge that TBI is potentially traumatizing for children and that it threatens the security of a child's life (Kieffer-Kristensen et al., 2013; Kobak, 1999; Bowlby, 1969). As these children interact with the brain-injured parent, they struggle to comprehend the post-TBI actions and attitudes of the parent, including: unsettling mood swings, inability to communicate clearly, and apathy towards normal life tasks (Urbach et al., 1994). Other researchers have found that approximately 10% of adolescents living with a parent who has a chronic medical condition are at a higher risk of stress and exhibit difficulties in adjusting to life

circumstances (Sieh et al., 2013; Sieh et al., 2010a, b; Verhaeghe et al., 2005; Visser-Meily et al., 2005). The further distanced children feel from their injured parent, the more likely they are to act out impulsively and exhibit behavioral concerns that were not present pre-injury.

Researchers have also found that adolescent response to TBI depends on the age of the adolescent at the time of the injury. Rolland (1997) argued that the developmental stage of the adolescent determines their conceptualization of the injury, affecting how deeply they are impacted by the TBI-P and also argued that a chronic medical issue involves the medical concern, the family member experiencing it, and the current life cycle of the family unit. Other researchers agree, finding that younger adolescents are psychologically less affected by parental illness (Visser et al., 2004; Kieffer-Kristensen et al., 2013). One interesting finding was noted by Kieffer-Kristen and colleagues (2013) who found that between 7-14 years old, adolescents do not experience the parental relationship in a vacuum, but with the interplay of social forces. Thus, the parent-adolescent relationship is not the only force affecting adolescent response to TBI, but environmental factors too, as adolescents in this age range must also deal with the threats to their sense of normalcy, security of their everyday lives, and reliance on others to get through the event (Kobak et al., 2006). While some researchers have found no meaningful difference in these behaviors between TBI adolescents and control groups (Uysal et al., 1998), others claim that TBI adolescents are an at risk group in need of further research (Urbach & Culbert, 1991).

### **Ambiguous Loss**

“It’s not my real dad” (Butera-Prinzi & Perlesz, 2004, p. 89). This statement of loss and living with an injured parent resonates mightily for adolescents who are not allowed to experience closure after a traumatic event. Ambiguous loss refers to the inability of the families of injured patients to mourn or experience closure related to the changes experienced by the

injured person. While fatal injuries allow for some semblance of mourning and closure, the adolescent in a TBI-P environment does not have the opportunity to experience it since the injured person is still living. While research is exceptionally sparse on ambiguous loss, researchers have been able to gently peer into the phenomenon, finding that personality changes in the head-injured parent is one of the most jarring changes that can result in ambiguous feelings of loss (Thomsen, 1984; Teasdale & Engberg, 2005a; Ponsford & Schonberger, 2010). Bereft of rituals to support them due to the loss being unverified or not final, families are left on their own. Because of the ambiguity, relationships dissipate as friends and neighbors do not know what to do or say to families with unclear losses. For all of these reasons, ambiguous loss is a relational disorder and not psychic dysfunction. The ambiguity ruptures the meaning of loss, so people are frozen in both coping and grieving (Gergen, 2006; Boss, 2006).

Prior research has found that grieving an ambiguous loss mirrors death-grieving models with one major exception, known as *mobile mourning*: the injured-parent might not return to their preinjury capabilities or personality, which creates a loss that is repetitive and requires the grieving process to be repeated indefinitely (Muir & Haffey, 1984). Consequently, adolescents are forced to deal with a never-final loss whereas their parent is physically present but psychologically absent. Kieffer-Kristensen and colleagues (2013) called TBI-P ‘invisible injuries’ as they do not change the outward appearance of the injured person, but do change their behavior and mood. Adolescents also receive less support compared to adolescents who lose a parent to death, further serving to isolate them when compared to other types of loss (Estani-Dufour, Chappel-Aitkem, & Gueldner, 1992; Boss, 1991; Griffiths, 1997). One important variable to keep in mind is that families might grieve a TBI-P event similar to how they would grieve an actual death (Muir & Haffey, 1984).

If a cyclical pattern of grieving occurs within a family unit and centered on a TBI-P, the emotional and support structures that are normally allocated for the adolescents of the family are being strained and reallocated to the incident and the injured parent. Such supports are often completely reallocated, making them unavailable to the adolescent(s) experiencing the TBI-P, further putting them at risk for adverse reactions to their growing levels of stress and frustration and without access to parental support or ways to cope. To compound the issue, the injured parent also interacts with and complicates the grieving process, taxing the adolescent with adapting repeatedly to ever-changing expectations (Verhaeghe et al., 2005). As children are put under stress, they are further tasked with redefining their realities in relation to the injury, causing them psychological distress as they recall simpler times (Kieffer-Kristensen & Johansen, 2013). In one study, researchers found that adolescents lived in a backwards-facing stance, grieving the loss of their old parent while simultaneously trying to accept the new parent and adjusting to devastating feelings of loss and grief (Butera-Prinzi & Perlesz, 2004).

In the existing literature, relatively minimal attention has been placed on feelings of ambiguous loss in adolescents who experience a TBI-P. Adolescents experience extreme feelings of grief and isolation (Boss, 1991; Rycroft and Perlesz, 2001; Butera-Prinzi & Perlesz, 2004), traumatic stress (Butera-Prinzi & Perlesz, 2004), and unresolved grief (Urbach & Culbert, 1991). Perhaps most disorienting for adolescents is the in-depth adaptation that must take place:

Particularly complex adaptation faces children dealing with the "changed" parent, who survives, undergoes partial recovery, but sustains behavioral, affective, and personality alterations. This transformation, in variable degrees, confronts the child with a different parent in the same body. (Urbach & Culbert, 1991, p. 26)

This type of parental outcome and adolescent reaction is striking and indicative of other research in this area, whereas adolescents are forced to mourn the old version of their parent while working through complex feelings of love, loss, anger, confusion, and acceptance of their changed parent (Tiar & Dumas, 2015; Charles, Butera-Prinzi, & Perlesz 2007).

### **Summary**

Acknowledging the stress that families undergo in a TBI-P event is foundational to further exploration of the idea of ambiguous loss. Families, acting as caregivers, undergo an incredible amount of stress and adjustment in the immediate aftermath of a TBI-P. Research has shown that this stress extends many years after the injury, too. Families and adolescents also exhibit signs of PTSD and must struggle with reconciling feelings of loss, change, and uneasiness regarding the injury. In turn, family systems are turned upside down as families struggle to redefine their normal and move to a new sense of normalcy. As a consequence, adolescents experience a feeling of ambiguous loss, whereas they are not able to fully mourn the loss of a still-living parent. This literature review has focused on multiple areas that are central to the phenomenon of ambiguous loss and how they interact with one another. A specific focus was centered on family stress and adolescent response to TBI-P, exploring the literature as deeply as possible. Through a review of the literature, issues surrounding stress, PTSD, system effects, and ambiguous loss were surveyed. Chapter three focuses on the methodology of this study.

## CHAPTER 3: METHODOLOGY

In the prior chapter, I explored the current literature surrounding parental traumatic brain injury and the many peripheral foci associated with the event, including stress, post-traumatic stress disorder (PTSD), system effects, and ambiguous loss. A parental traumatic brain injury (TBI-P) has major psychological implications for adolescents and these implications have the potential to be far-reaching as they enter adulthood and beyond. This research project aims to fill the gap in the literature and to push the research field forward by uncovering useful information that bridges the gap between TBI-P and the concept of ambiguous loss.

This chapter describes the general research design and rationale of the study, a discussion of the research design, a review of the research questions, and the role of the researcher. Next, the methodology of this project is discussed, including the selection of participants, the process and instruments related to data collection, and the steps taken to organize and analyze the data in order to answer the research questions. The chapter then discusses the trustworthiness of findings in relation to its qualitative design, concluding with topics on ethics and the limitations of the study. This research project aims to fill the gap in the literature and to push the research field forward by uncovering useful information that bridges the gap between TBI-P and the concept of ambiguous loss.

### **Rationale and Assumptions for Qualitative Design**

This dissertation used a qualitative case study design with participants ranging in age from 7 to 24 years old. Using interpretive phenomenology, this study was grounded in core components of qualitative research approaches and purposefully used these components to direct the study. First, the use of a qualitative design was appropriate for this type of research, especially as it related to giving voice to an often-silenced population of adolescents who

experienced a TBI-P event. Perhaps more importantly, the use of qualitative methods allowed me to measure ambiguous loss, an abstract concept, while also allowing me to develop a deeper literature base surrounding the complex issue of how adolescents experience the phenomenon (Creswell & Poth, 2018). Next, I chose to use a case study design as access to adolescents who experience a TBI-P was extremely limited by hospitals and other facilities. With such a limited pool of possible participants, a case study design aligned well with the desired outcome, which was to tell the stories of adolescents who experienced a TBI-P event. Further, I took an interpretive stance, which assumed that “reality is socially constructed and that there is no single, observable reality” (Merriam & Tisdell, 2016, p. 9). Since TBI-P’s influence all family members (Keiffer-Kristensen & Teasdale, 2012), this particular stance was useful in extracting the experience as told by the participants instead of relying solely on prior quantitative research to position this research. Through the use of a phenomenological approach, I sought to learn about the lived experiences of adolescents who experienced TBI-P and focused less on the theoretical underpinnings of their experience or to develop a conceptualization of that experience; their stories were more important than my abstract conceptualization of them.

### **Research Design**

Phenomenological research seeks to extract and make known how experiences are experienced and is a way for researchers to “look at what we usually look through” (Vagle, 2018, p. xii). Operationally, phenomenological research focuses on a single phenomenon and seeks to uncover the subjective experience of a phenomenon. In use, phenomenology is a “return to the traditional tasks of philosophy...and back to the Greek conception of philosophy” (Creswell & Poth, 2018, p. 76).

I used an interpretative phenomenological analysis approach. In interpretive phenomenology, the researcher is involved in a continuous act of interpretation while the approach is less about researcher rigidity and abstract conceptualization and more focused on how the phenomenon is lived (Vagle, 2018). With this approach, the process of the study could focus on the phenomenon and data, leading to a more clear understanding of the phenomenon and less on the discovery of some abstraction of that phenomenon. Before analyzing the data collected for this research project, it is important to understand the lens in which I view research as a whole. First, aligned with Guba and Lincoln (1989), I believe that reality is subjective and dependent upon the person experiencing it; there is no singular reality nor is there a way to generalize the human experience of one person to another. Second, for this research project, open-coding was utilized. Borrowing from grounded theory, I believe that a constant comparison approach was an important consideration whereas I could compare data, my understanding of that data, and the categories in a constant back and forth to ensure full coverage and comprehension of the phenomenon (Mills, Bonner, & Francis, 2006). Finally, I ascribe to the notion of theoretical sensitivity whereas I remained responsive to the “nuances and complexity of the participant’s words and actions” (Strauss and Corbin, 1990, p. 44) and continuously worked on reconstructing participant responses from the data I collected.

I chose this approach for three reasons. First, the constant return to collected data is essential to uncover true lived experience. This iterative process provided flexibility for different themes and findings to enter the research at any time while eliminating the rigid linear process found in other research approaches. Second, as TBI-P and ambiguous loss can be complex phenomena, I wanted to remain flexible to the findings and not be locked into an approach that will not let the data lead the process. Finally, using an interpretative phenomenological analysis

approach allowed me to focus on the actual experience of my participants. Since TBI-P and ambiguous loss are deeply personal experiences that are experienced differently by each person, this approach allowed the telling of those stories without the need to create abstract conceptualizations that theorize about the experience.

### **Research Questions**

The following research questions guided data collection for this dissertation:

Research Question 1: As it pertains to TBI-P, what is the influence of ambiguous loss when experienced during adolescence?

Research Question 2: When TBI-P is experienced in adolescence, how does the perception of ambiguous loss result in tangible consequences later in life?

Research Question 3: In what ways do adolescents experiencing ambiguous loss from TBI-P describe their family, self, and situation?

### **Role of the Researcher**

My role as a researcher was centered around my ethical responsibilities of collecting data and reporting findings as uncovered through my participants personal experience. However, there was much more to my role as a researcher than the idealistic and simplified statement presented above. My role as a researcher was two-fold. First, my main goal as a researcher was to tell the story of my participants that was both accurate and honoring of their experiences; I did not use my assumptions or personal experiences with TBI-P to play a role in the research. Further, I did not fit their experiences into a pre-formed expectation of findings, forcing conclusions to fit my expectations. Consequently, I let the experiences of my participants drive this research project, traveling along with their stories and letting them lead to a natural conclusion.

Based on Vagle's (2018) discussion of bridling and reflexivity, I worked to bridle my past experience with TBI-P and to let the participants' story speak for themselves. Bridling is to acknowledge the researcher's experience with a phenomenon and to explore preconceptions about it, allowing the researcher to remain uncompromised and open to alternative interpretations. In this sense, I acknowledged my personal and emotional connection to the topic and made mental strides to set aside that experience. Understanding that TBI-P events can be unique to each person who experiences them, I remained open to alternative experiences and outcomes which were bore out in chapters four and five. Along with bridling, remaining reflexive throughout the process involves "consistently examining how one's positionality, perspectives, backgrounds, and insights influence all aspects of a study" (Vagle, 2018, p. 14). My perspective as a TBI-P survivor required me to constantly set aside my experience and bias and to embrace the lived experiences of the participants. To do this, I explored their experiences while constantly reminding myself that my experience was unique to me and that my experience should not transform into bias. In turn, I opened myself up to alternative explanations when the data could not support a conclusion that aligned with my experience. As indicated in the opening of this research study, my personal experience of growing up with a brain-injured father was the driving force behind this study. Accordingly, I worked to bridle my experience and search for alternative experiences and explanations as they relate to this study. To this end, the results of the study support the bridling that occurred during the duration of this study.

### **Methodology**

The following sections outline the methodology used for this research study, including participant selection, recruitment of participants, data collection, instrument, and data management, data analysis.

## **Participant Selection**

The participants for this qualitative case study research project were selected for their lived experience with TBI-P in adolescence. The participants range in age from 7 to 24 years old and all of them experienced a TBI-P event in their elementary or middle school years.

Participants for this study are made up of two sets of siblings. The youngest participant, Maggie, was included in the research after her mother recommended her participation and while Maggie did not fit the definition of an adolescent since she was pre-pubescent, her inclusion in the study added depth to her siblings experiences. Originally, the goal was to focus exclusively on adolescents but was expanded to include young adults who went through the traumatic event. Through this change in focus, I was more able to comprehend how the TBI-P affected them longitudinally, especially focusing on how the injury and the concept of ambiguous loss might have played out along the way; this minor change in participant selection allows for more breadth and depth of data. The participants for this dissertation were selected using purposive sampling with the singular requirement of having a parent with a moderate to severe TBI. For participant demographic details, see Table 2.1, found at the end of the study.

## **Recruitment of Participants**

When I began recruiting for this project, I emailed three local and regional hospitals to find referrals, specifically sharing my research details to gauge interest. However, due to the Health Insurance Portability and Accountability Act (HIPAA) restrictions, I could not gain access to any participants nor were any of the hospitals allowed to direct me to any other resources. I then began to email local and national support groups in hopes of finding participants for my study; I contacted 10 support groups and organizations dedicated to supporting TBI patients and their families. To find support groups, I found a list of TBI groups

through the Brain Injury Association of America and contacted groups in North Carolina, South Carolina, Virginia, and Oregon. While many groups declined to participate or assist in locating participants, three groups agreed to participate and I worked with group leaders to get in touch with possible participants. When they agreed to participate, I sent the group leader more detailed information about the study that would be passed on to potential participants. If the potential participants agreed to be in the study, the group leader would send me their email address for follow-up. Eventually, from these support groups, I secured multiple participants for the study. Two support group leads that I collected were eliminated from consideration for different reasons, with most of the exclusions being based on the severity of the brain injury, with many possible participants reporting mild TBIs instead of moderate to severe injuries.

### **Data Collection**

As stated previously in this chapter, this study was influenced by phenomenology with a focus on the lived experiences and meaning-making of the participants. Data for this study was collected through the use of semi-structured interviews and was conducted over two sessions. The first interview lasted approximately 45 minutes with a follow up interview of varying length, dependent on the first interview and any lingering questions. During each interview, the audio (or video for participants from out of state) was recorded along with notes. My notes focused more on the responses of the participants and less on taking word-for-word notes. I decided to not take copious notes as that could “reduce the openness and immediacy” of the exploration of the phenomenon (Vagle, 2018, p. 88). This type of focus allowed me to follow-up on responses and to probe deeper when necessary in order to focus on the participant’s response, not my own methods or external focuses. Using in-depth interviews as my primary source of data, the qualitative approach of this study was strengthened as the project centered on the exploration of

a phenomenon (Moon, Dillon, & Sprenkle, 1990). To increase the validity of the findings, I used member checks to confirm my analysis of the data, with both member checks serving as confirmations to my analysis with no changes needed based on those checks. See table 2.2 for a detailed listing of total interview times for each participant, found at the end of this study.

### **Instrument**

The instrument for this research project was an IRB-approved semi-structured interview protocol. Aligning with previous qualitative research into TBIs, self-reporting interviews have been the accepted choice of data collection for many years (Bishop & Miller, 1988; DePompei & Zarski, 1991). With a semi-structured approach, I designed the interview with primary questions and follow-up questions with a focus on flexibility during the interview. For instance, if the participant phrased a response that intrigued me, the semi-structured format of the interview would allow me to follow-up and explore that question, possibly uncovering information that was not intended through the original question.

Vagle (2018) acknowledged that while the interview is open-ended, there are still boundaries and norms of interviewing that keep the research-focused, reminding researchers to let the flow of the interview occur within predetermined boundaries set by the researcher. Perhaps the biggest focus of a phenomenological research project is the constant reminder to “look at what we usually look through” and to “pay special attention to the moments in which you assume you know what something means and open it up through questioning” (Vagle, 2018, p. 88). By remaining cognizant of the participant’s experiences and responses to questions, I used the semi-structured format of the interview to constantly expand on questions and probe for deeper understanding. This sort of reflexive interviewing allowed for great flexibility and the ability to pursue understanding in ways that a structured interview or quantitative approach could

not replicate. The protocol included initial broad questions and then proceeded towards the specific TBI-P event. This allowed me to obtain more data about participants' pre-injury, during the injury, and post-injury. The questions used for the interviews are found at the end of this dissertation (Appendix A).

### **Data Management**

I took multiple steps to maintain the security of the data and confidentiality of participants. All notes and audio recordings were stored securely on my computer and backup copies saved to an external hard-drive. First, all audio and written data that I collected was stored on my personal computer with password protection. I also stored backup copies of my work on a secure external hard drive that was password-protected. Further, all personal information was removed from the transcription of the interviews and replaced with aliases to protect participant confidentiality. After transcribing the data verbatim, all audio recordings were permanently deleted from my computer. Per approval from the university's Institutional Review Board (IRB), the data will remain on my personal computer and will remain password-protected for five years. At that time, they will be permanently deleted from my computer.

### **Data Analysis**

Informed by Mills and colleagues(2006), I first interviewed participants and recorded their responses, either through audio or video recordings. After each interview, I transcribed the audio recordings verbatim into NVivo 12. To import the interview transcription into NVivo 12, I listened to the interview recordings and typed the interview word-for-word directly into the program including any pauses or non-verbal cues in the participant's responses. Responses from the first interview were used to inform the final interview, whereas the same interview process

occurred. Each interview was then coded within NVivo 12 and coded multiple times. Codes were continuously collapsed until a final few remained.

Procedurally, I first read through the transcribed recordings to reorient myself to the data I collected. During this initial read-through, I did not code or organize my data, but rather read the transcript with a focus on what participants discussed in general and what I noticed. On the second read-through, I began sorting similar words, concepts, phrases, or experiences into initial themes.

After my second read-through, I began to organize my findings into primary themes, collapsing similar themes into one another. During this process, I looked for themes of similar concepts and combined them with others. This process allowed me to create a manageable number of themes and to focus my findings on the major takeaways of the participants' experience.

## **Trustworthiness of Findings**

### ***Credibility of Findings***

I helped to establish the trustworthiness of my findings in various ways. First, the analysis of data underwent member checks where my analysis was checked by my participants to ensure I represented their experience correctly. After my data analysis was complete, I shared my findings with the participants to gather their feedback. In the case of younger participants, I shared the findings with their non-injured parent. During this process, I was most interested in ensuring that their story and experiences were accurately reflected through my retelling of their experiences. By taking this step, I helped ensure that my initial and lasting findings aligned with participants' lived experiences (Merriam & Tisdell, 2016). Second, I looked for contradictory evidence and included these findings in the discussion chapter. By acknowledging and exploring

alternative or unexpected findings, the credibility of the study was enhanced. Next, I placed my findings in the context of the existing literature to ensure consistency between what researchers already know and the findings of this study. By comparing my findings with the existing literature, I worked to triangulate my data to ensure quality and rigor (Merriam & Tisdell, 2016).

### ***Transferability of Findings***

While some types of qualitative research are not interested in generalizing findings to a greater population but focused on transferring findings to other cases (Tobin & Begley, 2004), the findings of this research will transfer in some cases. However, since TBIs are unique and dynamic, no finding from this study should be assumed to apply to any other TBI experience; there are too many variables for such comparisons. The focus on transferability requires a tight focus on the topic of research and the participants. To strengthen my research, I provided thick descriptions of the participants, the TBI-P environment, and the TBI-P experience as told by them. Nowell and colleagues (2017) argued that such thick descriptions will allow future researchers to transfer these findings to their particular research interests and allow them to judge the merits of my findings.

### ***Dependability of Findings***

Qualitative inquiry requires that the research process should be logical in its design. When future researchers read through my research design, processes, and findings, they should be able to easily trace the progression from the research questions through to the findings through the clear documentation that I provide (Tobin & Begley, 2004). Consequently, my research questions are clear, my methodology is explicit, my participants checked my grasp of their experience, and my discussion will be based on the facts. The end goal of dependability as it relates to findings from this study is for future readers to peer into the research process,

understand how and why it was set up this way, and agree that this was the best approach to use for this particular research problem (Lincoln & Guba, 1985). To ensure dependability, I was explicit in my explanations and reasoning in each step of my research, especially in the discussion of findings.

### ***Confirmability of Findings***

Confirmability is the final focus area in building the trustworthiness of my research and focuses on whether my findings and subsequent interpretations are grounded in the data (Nowell, Norris, White, & Moules, 2017). This particular area requires me to clearly link my interpretations and conclusions to the data and to explicitly join them together (Tobin & Begley, 2004). While Guba and Lincoln (1989) argued that confirmability is achieved when credibility, transferability, and dependability have all been met, I disagree. I conceptualize confirmability similar to Koch (1994), whereas I left a decision trail regarding my choices during the research process: “A decision trail provides a means for the researcher to establish audit trail linkages. Leaving a decision trail entails discussing explicit decisions taken about the theoretical, methodological and analytic choices throughout the study” (p. 92). To functionalize the decision trail, I used memoing as a way to track my thoughts, assumptions, and any changes in my thinking. To ensure that my research is confirmable, I followed best practices in qualitative research, including constantly returning to the data to ensure interpretation and explicitly returning to my theoretical, methodological, and analytic footings to ensure alignment and focus.

### **Ethical Procedures**

To ensure ethical protections for my participants, IRB approval was obtained before data collection began. With participant risks in mind, I followed the three main principles of

protection: “Respect for persons, beneficence (minimal risk or risks that are justified), and justice (no exploitation of persons)” (Roberts, & Hyatt, 2019, p. 146). To this end, I followed all best practices in protecting the participants in my study. Aligned with standard practice, the name and any other identifying information regarding my participants were changed. However, the time since injury and age at the time of injury were kept the same in order to more fully present my findings and ensure transferability (Minichiello et al., 1995).

Before participating, participants (or their guardians if under the age of 18) reviewed and signed an informed consent form that explicitly explained the research process and associated risks. While there were no major risks involved with this qualitative, interview-driven research project, no project is ever risk-free. While there were no physical risks for my participants, there were risks that come along with recalling a stressful life event from their childhood. The participants could experience stress or anxiety in recalling their experience, perhaps bringing up unwelcome memories from a stressful time in their life. To address the possibility of adding undue stress, it was made clear to the participants that their continued involvement during the interview or project could be stopped at any time and that they could refuse to answer any triggering questions. During the interview, I remained hyper-aware of body language and/or voice intonations as I approached possibly stressful questions, using my experience with TBI-P as a guide. As I engaged in this study, I was aware that qualitative research has the opportunity to bring out ethical concerns, including issues around maintaining confidentiality and my impact on the participants (Mahnaz, 2015). While there was minimal chance of confidentiality or negative impacts with this study, I was still aware that other issues could emerge during the research process.

### **Limitations**

There are limitations to the qualitative nature of this research project that should be considered. First, as a case study, the sample size of this study was a limitation. While I expect the results (or at least parts of the results) to transfer to other TBI-P adolescents, the story of a participant might not align with others since TBI-P is a deeply personal and individualized experience. The sample size was extremely limited due to access issues and the inability of hospitals or other providers to assist in participant recruitment. Case studies have limitations, too, mainly that they create difficulties in establishing cause-effect connections (Queirós, Fariol, & Almeida, 2017). Second, as this project relied on the retelling of an experience, there is a chance that some memories or events could be misremembered or exaggerated. If an experience seemed irregular or acted as an outlier to what the existing literature has shown, further exploration on that experience helped to offset this risk, including verification through further probing questions or follow up interviews with associated parties to verify what has been said.

### **Summary**

This research project implemented an interpretive phenomenological approach and utilized a qualitative approach to access an often-unseen population. By using qualitative methods to understand the adolescent experience with TBI-P and ambiguous loss, I was able to see the experience through the eyes of those who lived it. Using a qualitative approach allowed me to peer into the phenomenon through the stories of my participants and to envelope myself in their world. Noting my personal experience with TBI-P and exploring my feelings about the topic, I remained reflexive and bridled my personal experience. Through in-depth semi-structured interviews, I explored the stories of my participants while ensuring the findings were trustworthy and my dealings with them were ethically-protected. The following chapter discusses the findings of the study.

## CHAPTER 4: FINDINGS

This study examined the influence of ambiguous loss on five participants who were adolescents when they experienced a TBI-P while living at home. Ranging in age from 7 to 24 years old, data from participants indicated different challenges that are unique to parental traumatic brain injuries, including feelings of loss and struggles related to working through emotions. Using semi-structured interviews as the only source of data, I answered the research questions by examining the experiences of five participants. This study was grounded in the following research questions:

Research Question 1: As it pertains to TBI-P, what is the influence of ambiguous loss when experienced during adolescence?

Research Question 2: When TBI-P is experienced in adolescence, how does the perception of ambiguous loss result in tangible consequences later in life?

Research Question 3: In what ways do adolescents experiencing ambiguous loss from TBI-P describe their family, self, and situation?

To answer these research questions, each participant will be discussed in-depth, including an introduction to each participant and their experience with TBI-P. Unique to each person who experiences them, TBI-Ps are viewed differently by the primary caregiver and the adolescent children in the home based on their lived experience. Thus, a well-rounded introduction to each participant is beneficial to fully understanding their stories and how a TBI-P experience could lead to an ambiguous loss. Detailed introductions to each participant will help to provide descriptions of them, the TBI-P environment in which they lived, and their TBI-P experience as

a whole, including feelings of ambiguous loss. In turn, their answers and experiences will guide the analysis and discussion to follow in Chapter 5.

### **Participant 1: Elaina**

Elaina was referred to me for inclusion into the study by a mutual friend who had worked with Elaina's father in a rehabilitation clinic as he recovered from his TBI. As I recruited participants, I reached out to Elaina to gauge her interest in participating in the study. After sharing the purpose of the study, she enthusiastically accepted and was excited to share her story in hopes that others might learn from it. From our first conversation, I could tell that Elaina was passionate about the topic of TBIs and that her unique story had the potential to further enhance our understanding of how adolescents experience a TBI-P. Part of this passion was based on Elaina's vocation as a teacher in the southeastern United States, allowing her to see how a student might struggle with traumatic events and how those events could influence student behavior and academic performance in the classroom. The other part of her passion was based on her experience during her adolescence as she grew up with a brain-injured parent.

Aside from being the oldest participant at 23 years old, Elaina's story was unique in numerous ways. In 1991, before she was born, her father suffered a severe TBI while working as an airline mechanic on the overnight shift. Descending from a ladder, his leg became tangled with a cable, and he fell head-first into the concrete floor below, suffering a TBI and being simultaneously electrocuted. In the immediate aftermath, Elaina's father slipped into a three-week coma, re-emerging to consciousness with various mental deficits. The most serious of these deficits included that her father had to relearn how to speak and how to recognize common items, such as a television remote. As a result of the TBI, the injury also caused her father to suffer from epilepsy, which progressively got worse over the years. In 2007, when Elaina was

nine years old and in fourth grade, her father had to have a left temporal lobectomy and partial removal of the hippocampus which caused further stress on the family, including more communication issues and conflict within the family. As a result, Elaina's story is interesting since she lived with a brain-injured parent up to age four and then lived with a brain-altered parent since then.

### **RQ1: Influence of Ambiguous Loss**

#### ***Setting the Stage: Before Her Father's Surgery***

During Elaina's interviews, a story began to form, starting with the brain injury, transitioning to the subsequent brain surgery, and concluding with feelings of ambiguous loss experienced by Elaina that have had lasting impacts on her life. When she spoke of her memories before her father's surgery, she recalled a different and more healthy view of life. Discussing what life was like before the injury and as a fourth grader, she relayed a positive self-image: "...I think I was very confident socially, academically, and emotionally." Elaina's self-image was positive even though her brain-injured father was different from her friends' fathers, something we would discuss later in the interview. However, she reported that she did not realize her father was different until later in her life, noting: "he had it [a brain injury] so long before...even before my mom knew him, technically, it's just the way things were." In this normed version of her family, an injured dad who experienced medical issues and episodes was a normal part of childhood. In turn, Elaina noted her family was "Consistent. Very supportive. And, more like a unit." Remembering her father specifically, she recalled her dad in fond terms, although noting the differences she saw pre- and post- surgery, sharing:

Well, there was still a vast contrast between before and after surgery. Because, I'll be honest, I think the surgery had a much more impact on my life than the brain injury, since

I didn't know that contrast. My dad originally was...a very just happy go lucky, supportive guy. Like, excited to be with us...Like, outgoing guy.

This image of a happy father and family was mentioned later in our conversations too, with Elaina remembering that her family was like a singular unit, working towards the common good of the family:

Everything...it felt very...like, nuclear family. And once again, I was a lot younger, so I think there was rose colored glasses when you look at it. But everyone, I felt like, was on equal standing with each other. Like I had just as good a relationship to my brother as I did with my mom as I did with my dad.

As Elaina discussed her memories of her family moving through life as a unit, her words were tinged with a sense of loss, indicating that a negative change had occurred after the surgery. Data analysis from Elaina's interviews indicated that her comments aligned with signs of ambiguous loss, from accepting an emotionally ever-changing father to living a life that resided in the emerging, indistinct idea of what a normal parent-child relationship should look like. Living with a brain-injured father since she was born, she did not know any contrast to what a normal dad should look like. In her words:

It's just kind of the way we lived because it happened before we were born. I thought everyone's dad had seizures, I thought that was just standard with the unit that it came with? You know? [laughs]. That everyone grew up with that, almost like a cultural thing in a way. And, like, I thought everybody's dad has seizures, like, they do that little weird dance, ya know, and say those funky words. That's just how I grew up.

For her entire life, she had no way of contrasting what was considered a normal childhood, such as not having a brain-injured parent, and she was conditioned to accept the normalized version of

her life. This type of normalization included a father who acted differently than her friends' fathers. She even brought this idea up later in our interview, noting: "I started seeing what their dads were like more, because I would actually go over to their houses and see, oh...not all dads are like this. That's weird. And I think I got more jealous than anything." She continued with this thought, noting: "You saw more things in relationships with friends, like that jealousy of like, why's your dad normal? Why does my dad have an injury?" Initially, her sense of normal was not challenged until she was exposed to different experiences that caused ambiguity to enter the picture. Consequently, her comments provide evidence of living with an ambiguous loss as she worked to grieve and adjust to her father and his new and changing emotional state.

Throughout our discussions, Elaina mentioned multiple times what it was like to grow up with a brain-injured parent. Interestingly, one thing that kept recurring in our conversation was the idea that living with her father was like living with many different people. "He's been many a different people...And it was like, that is not the guy I know...My mom always jokes that she's been married to five different men because of how my dad has been." Having to live with an emotionally ever-shifting father was a source of contention in their relationship, causing feelings of ambiguous loss to be present. The loss was ambiguous as Elaina was not able to fully mourn her father since he was still alive but forced to accept many different versions of him while mourning and remembering her father as he was before the surgery. Consequently, as their relationship shifted, Elaina was tasked with adjusting her expectations and accepting her reality, all while mourning her still-living father: "Like, he's not going to be the same that he was before but he's going to be ok." This type of positionality within their father-daughter relationship was required of Elaina without her consent, indicating a possible connection between the adjustment of her expectations and the idea of suffering an ambiguous loss. Her father was acting

differently, constantly changing, and in need of acceptance that fell squarely on the shoulders of his family. Consequently, her post-surgery father might not have been the same person she so fondly recalled from her childhood years.

### ***Transitioning to a New Normal: After the Surgery***

As Elaina transitioned into discussing her life after the surgery, a fuller picture began to emerge that she might have experienced an ambiguous loss. In 2007, after her father's surgery, she noticed a negative shift in multiple areas of her life, including her emotional state, her academic performance, and her family's feeling of cohesiveness. These negative stressors began to feed into a feeling of loss for her, one that could not easily be described. One story Elaina shared really showed the contrast to her pre-surgery father:

And...[he] was just so irritable and angry. And it would just be the oddest things that would set him off. Like, I remember we were at Disney World and my brother asked for a snack that he had saved from earlier that we had brought. And he just lost it. He just went into this whole rage and stormed off, and we didn't see him for the rest of the day.

Such outbursts and changes to her father's demeanor weighed heavily on her. In turn, emotionally, Elaina reported acting as if everything was business as usual, but internally, she was struggling with the swiftly changing environment around her: "Your dad had a brain surgery. You don't know what that is. You think, is he on the brink of death? Like, what's going on here?" As a fourth grader, perhaps it was impossible to grasp the severity or possible negative outcomes of a major brain surgery, but Elaina was grappling with the idea of loss already, wondering whether her father might die without seeing her again. Her statement above indicates the confusion that an ambiguous loss could cause: "Like, what's going on here?" Was she being asked to accept that her father might die or that she needed to mourn her father, even though he

survived? The confusion surrounding her thought process points to the possibility that she was experiencing an ambiguous loss and did not know exactly how to deal with it.

Academically, Elaina experienced a sharp contrast and negative shift to her pre-surgery image of herself, sharing:

He had the surgery and I acted like everything was ok, but I wasn't turning in stuff. I wasn't turning in homework. I wasn't necessarily acting out but I wasn't engaging in class. And I just couldn't...I was like a mess. I would do the homework, I just wouldn't turn it in.

Elaina was struggling with her dad's surgery and working through an ambiguous loss, causing her to stumble into negative cycles in her academic pursuits. Notably, while her attitude and behavior had not necessarily changed, her willingness or ability to stay focused on academics was a challenge. As these behaviors were not reported before the brain surgery, they may have been influenced by her feelings of ambiguous loss.

Further, Elaina recalled an instance in her post-surgery academic journey that has had a profound impact on her to this day. She struggled in the fourth grade with her academics and was labeled as a bad kid, someone who did not care about school or giving her best effort. "And it's so funny how those things stick with you because I specifically remember I was put at basically the bad people's table with kids." Recalling her feelings of being mislabeled, Elaina shared:

And, I remember the emotion. Even looking back, I was like, I'm not gonna say necessarily I was traumatized by it...but it definitely shaped me in a way, where I was like, oh that was not a good year.

As Elaina struggled with being mislabeled, she looked back on this time as a wakeup call that something had to change: "And so, I think there was a rude sense of, ok, maybe I am special. I

can do this, you know. And, I don't have to be the kind to flunk out fourth grade." Turning her feelings of ambiguous loss into positive change, Elaina eventually returned to her pre-surgery form and began excelling at school once again.

Finally, Elaina sensed and experienced a shift in her family's cohesiveness after the surgery, something she struggled with throughout the years after the surgery. As Elaina grew up with a nagging sense of ambiguous loss, her family unit concurrently struggled with the same sense of loss: "I would say I think because it shifted the family dynamic so much...When the family dynamic shifted, I felt like I needed to take control as the older sibling of the family." Consequently, as a fourth grader, Elaina was forced to grow up much quicker than her "normal" friends and experienced fresh challenges as she worked to navigate her new and constantly evolving family unit. Almost a year after the surgery, the once-close family unit was beginning to experience stress, leading to a different evaluation of Elaina's family compared to before the surgery:

And after 2008, it felt very divided. It was a team of three versus a team of one. And I think even though my dad may not remember specifics or memories from that, I feel like he still feels that divide still to this day.

Such division in the family unit led to further feelings of isolation for Elaina, her mother, and her brother. In turn, she mourned the loss of her once-close family unit and struggled with the loss of her still-living father, a hallmark experience of ambiguous loss. The loss Elaina experienced was not final nor clear, which resulted in ever-shifting realities for her to work through and accept, all while balancing her feelings for reality against her memories of better times.

***Time Heals All Things?***

During our interview, Elaina reported that her relationship with her father was on more solid ground and unlike any other time since the surgery: “I feel like the dad I have now is the closest I have ever had to a normal dad. Thankfully I do get that relationship that I never thought was imaginable before.” This is a large shift in their relationship as there was a time that Elaina did not want her dad to be very involved in her life due to the stress and family damage that the surgery had caused over the years. It seemed as if Elaina had given up hope that her dad would ever recover to a point where their relationship could be salvaged:

It’s funny...before, I never wanted him in my wedding. He was there, but I didn’t want him to walk me down the aisle. I didn’t want the daddy-daughter dance. And now, we’re planning what song we want to do our father-daughter dance to. So it’s funny how it just kind of comes around and we can kind of build off those things once you kind of process things.

At a certain point in their relationship, she had already written him out of her future plans, instead intending to move forward without her father’s participation or interaction in her life. I coded this idea of parental loss as “acceptance of a new father” as Elaina accepted that her father would not change into someone she recognized as a legitimate father. Elaina was going to move forward in life without her father, much like someone might if they had experienced a permanent loss. Aligning with the idea of ambiguous loss, it makes sense that she was suffering from an ambiguous loss which looked very much like non-ambiguous loss. If her father had passed away from his surgery, Elaina might have acted in a similar way, choosing to move forward no matter if her father was involved or not. This evidence indicates that Elaina was working through an ambiguous loss.

Pressing further into the changes her father experienced and the seeming return to a sense of normalcy in their relationship, Elaina noted an interesting analogy:

Yes, it's like climbing Mt. Everest. You get a couple of areas, where you're like...there are sometimes that are very strenuous and hard but you have other times where it kind of levels out and you can kind of enjoy the view and appreciate how far you've come.

Because there's the process of, okay...I had to process what happened, like that ever going grief, but my dad changed into so many people.

Statements about her recurring grief aligns with the definition of ambiguous loss. Specifically in the quote above, Elaina is stuck in a sense of ambiguity about her relationship with her father. Indeed, bridges were being rebuilt in the most recent iteration of him. However, she also had to reconcile her feelings about her dad and their complicated history. Thus, she was dealing with her relationship with her father while struggling with the ambiguity that their relationship created over the years. If her father were to have passed away from his surgery, Elaina might have experienced some sense of closure. However, since he did not pass away, her constant grief and feelings of loss align with the concept of ambiguous loss.

### ***Feelings of Ambiguous Loss***

Elaina made note that she felt as if she had experienced a loss of some kind, most recently after her father fell ill on an international work flight. While returning home from overseas, Elaina's father suffered six grand mal seizures on his flight. After each seizure, an on-board EMT monitored his vitals and noticed his oxygen level decreasing to dangerous levels, eventually forcing the plane to make an emergency landing on the west coast. Rushed to the hospital, her dad was in critical condition and placed into a coma for a few days due to concerns about his lungs. However, after a week, her father recovered. In the interim, when the plane

landed, Elaina and her family rushed to his side from the east coast, which brought up memories of his initial surgery and all the time spent at the hospital years ago. She mentioned how the recent event brought up memories of his surgery and how that triggered feelings of loss once more: “But it was definitely kind of grieving that, like, I’m not going to have a normal dad and he will never be the way he was [in] 2008.” The reoccurrence of health problems experienced many years ago around the time of the surgery resurfaced again, as Elaina was once again dealing with an ambiguous loss:

Because, you’re right...there were those shifting sands of we didn’t know what the turnout was going to be like, what that was going to be like. So, was he going to survive it? Survive it with a lot less capability, what that was going to look like? And it was just like a...I’m not diagnosed with depression and I don’t want to use that term, but like, just a dark cloud of lethargy almost. Not wanting to do anything, on the verge of tears all the time. And I couldn’t focus on anything in my life, it was just so scatterbrained. And I couldn’t work well, couldn’t teach well.

This time, she feared the loss of her father once more, struggling to deal with the seemingly-shrinking chance that her father would never return to any sense of pre-surgery normalcy. In her own words, Elaina again referenced her grief: “Like, it did feel like I was grieving something because it would just come in waves and I couldn’t help it. So definitely have been trying to work out of that.”

The primary finding to this research question can be thought of as longitudinal, whereas the initial surgery caused an immediate reaction in Elaina through a negative shift in her emotions, academic performance, and family relationships. However, these initial reactions stabilized and improved as time went on. While all of the initial reaction areas settled and life

returned to an altered sense of normal, Elaina was once again forced to deal with her emotions when her dad fell ill again:

Well, it's one of those things where it almost feels like its baggage because I don't know...February of this year was very jolting because it's like, I want to really invest in this relationship, but one: you don't remember my childhood for the past 15 or 20 years. Second of all, there is this kind of like...what if you lose it again? What if something happens? And then, how invested am I going to get in this relationship with someone who might not stay the same over the next five to ten years?

In her mind, she was struggling with all of the emotional baggage that was caused by the initial surgery. Her feelings of ambiguous loss and dealing with a forever-changed parent are central to her thoughts here. Further, she went on to debate the merits of pursuing a relationship with her father after his latest health struggles while still struggling with the aftermath of the initial surgery. Specifically, she was living in ambiguity in unison with her dad, who cannot recall her childhood in a meaningful manner, which caused further stress to an already-fractured relationship. Looking forward, she questioned the usefulness of investing in a relationship with her father who, in his ever-shifting mental state, might not be the same person. Living in such ambiguity stems from experiencing an ambiguous loss, whereas the unclear nature of the loss drives most aspects of her relationship with her father, negatively influencing major areas of their relationship.

Beyond the relational struggles experienced by Elaina and her father, the ambiguous nature of her loss created other issues in her life. Because Elaina was struggling with the surgery during her adolescent years and labeled as a bad student, she remembers being shaped by her experience of being labeled as a bad kid: "It's just, I just...I didn't have the...have the mental or

emotional capacity to make good decisions. I think that's what it was." As she struggled to come to terms with the loss of her still-living father, her academic performance began to decline and to this day, the influence of her loss and the issues it caused still hold an emotional spot for her. Could her performance in school and label as a bad student been related to something other than her dad's injury? It's unlikely, based on her confirmatory description of herself immediately after the surgery:

I was very, a lot more, reserved and distant from people. Like, obviously, I'm very chatty, was before. But, I put a lot of distance between me and my friends. Things like that. I usually would be the first one to raise my hand with the answer...did not engage in conversation with the class at all.

Because of the injury and because of the ambiguous loss she was forced to process, her behavior in school had changed. The catalyst could have been her father's brain surgery and the consequent ambiguous loss she experienced.

Emotionally, Elaina began to internalize her feelings based on her father's changed demeanor. As she began to further hold in her feelings of loss, she found herself more isolated from her father. Through our conversations, we talked about the emotional toll that such an ambiguous loss had on her and she clearly laid out the emotional issues she has with her father:

He can't remember any of it [himself before the surgery or since], he doesn't remember how he used to be. He doesn't remember the effect that it took...he doesn't actually remember a lot of our childhood. It's hard to have conversations about forgiveness with someone who doesn't remember what they did.

In her situation, Elaina is forced to carry the burden of her relationship with her father as he is unable to remember or carry his emotional weight in the relationship. Not being able to

remember his daughter's childhood, Elaina is the only person left in the relationship who can salvage it. However, with the loss that has occurred, is a one-sided relationship worth the work to her? As Elaina got older, she became convinced that the relationship could never be the same as it was before the surgery; the damage had been done to her family unit. Consequently, she was again forced to bear the emotional weight that had developed, pushing her to envision the dissolution of her family: "So I went through high school fully confident in my parents were going to get divorced as soon as my brother graduated high school. Like, it was just going to happen, you know?" Not only was Elaina dealing with the cyclical feeling of loss as her dad endured many changes, but she also had to live with ambiguity as it pertained to her family itself. Wondering whether her family would remain together increased the feeling of ambiguous loss in Elaina and led to further stress.

### **RQ2: Tangible Outcomes Pertaining to Ambiguous Loss**

Discovering that Elaina went through an ambiguous loss was an interesting finding. However, can an abstract concept like ambiguous loss result in tangible consequences later in life? Since loss resides in the conceptual realm, it was important to explore how the idea of loss could lead to real-world outcomes. For Elaina, she experienced tangible outcomes related to TBI-P in various areas of her life, including her personal life, professional life, and emotional life.

Personally, the ambiguous loss that Elaina experienced resulted in a feeling of a lost childhood. As a fourth grader, she was tasked with processing her feelings and sorting through an altered family structure while simultaneously trying to salvage any sense of normalcy. Once the injury happened, Elaina sensed the changing family dynamics and felt like the next caregiver in line after her mother. Consequently, those forever-altered family dynamics would lead to

some directly relatable outcomes. First, Elaina noted that her decision making was changed because of the loss she experienced:

I would say I think because it [the surgery] shifted the family dynamic so much, it changed how I make decisions as a teenager and as an adult. I am very much a perfectionist, I am a go-getter type of person, so I don't sit around and wait for things to happen. I go, "I'll jump in and be the leader." When the family dynamic shifted, I felt like I needed to take control as the older sibling of the family, things like that.

In terms of tangible outcomes, her decision-making was affected soon after the surgery. Instead of serving as a passive participant in the story of life, she was forced to emotionally mature earlier than children with non-injured parents.

In turn, she decided to serve as a sort of counter-weight to her father's changing personality and her mother's stress as a caregiver, acting as a surrogate mother to her younger brother. Elaina discussed this idea by giving me a glimpse into her relationship with her brother:

Yeah, it's just interesting... But, my brother is younger, and it's so funny because my dad really butted heads against my brother. Like me, I was pretty okay, I could kind of get through...the thing was I was old enough to make better decisions, what to say, what to do versus my brother who was just like headstrong, who was like, no...[unintelligible whispering]. And, for a while in high school and middle school, but Paul would go through this cycle where he would start to try, he would do something, and I'd be like "it's not gonna work...I've done it too, sorry, so I can stop trying." I just kind of had a very distant relationship with my dad. My brother would keep trying to like, re-...then it would blow up in his face, and he'd be like, "I don't understand." Like, how did you not see that coming? Like, are you blind? We all see it coming. You get mad, he gets mad. It

just spirals out. And so, being the older one, I felt like I didn't only have to manage my situation but manage my brother's situation and try to look out for him...it's just that teenage boy brain.

In this instance, because of the ambiguous loss and the changes the surgery produced in her father, Elaina was forced to abandon her passive role as big sister and she instead worked to be the best big sister she could be to her seemingly defenseless younger brother. Because she experienced an ambiguous loss and could not define nor mourn her loss, she experienced a tangible outcome that is present to this day, feeling like the protector of her younger brother.

Professionally, Elaina directly connected her childhood experience with a brain-injured parent to her chosen vocation, teaching art at a high school in the southeastern United States. For Elaina, becoming a teacher was a response to the loss she felt as a child. Discussing her experience in elementary school and immediately after her father's surgery, she was quick to point out that she was a different person before and after the surgery. Before the surgery, she recalled herself as "...very confident socially, academically, and emotionally." After the surgery, her world was thrown into chaos: "When you see...when you are in that hospital for a couple of weeks and you're going in and out...your dad had a brain surgery. You don't know what that is. You think, is he on the brink of death? Like, what's going on here?" From that point, she was labeled as a bad student as her teachers were not aware nor did they understand what was happening in her personal life. From this treatment, Elaina reports feeling and thinking much differently as a teacher:

I think I empathize a lot more with people than I did before because I didn't really understand. But I have a lot more empathy. I...professionally, I give my heart out to my students. Like, they don't know this, but I would put my life on the line for every single

one of them. I would do anything because I...while we may not all have the same story, I know what that turmoil looks like.

In regard to tangible outcomes, Elaina is clear that her enhanced empathy for others is a direct outcome of her experience in school and how she fell through the cracks immediately after the injury. This finding relates to the concept of ambiguous loss as no researcher has directly connected ambiguous loss experienced in adolescence to a tangible outcome.

### **RQ3: Descriptions of Family, Self, and Situation Related to Ambiguous Loss and TBI-P**

Elaina had created definitions of her family, self, and situation based on her experience with TBI-P and ambiguous loss. In this sense, the unclear loss of her still-living father helped shape her perceptions of her reality. Speaking to her description of her family before the surgery, the idea of a “nuclear family” was at the forefront. Each family member cared for one another and all were viewed as equal contributors to that family unit. After the surgery, however, Elaina’s family felt fractured: “And after 2008, it felt very divided. It was a team of three versus a team of one. And I think even though my dad may not remember specifics or memories from that, I feel like he still feels that divide still to this day.” Once the surgery occurred and her family realized her father was not the same person as before the surgery, the family unit splintered into an “us versus him” setup, which persists in some form to this day. The relationship became more about managing her father’s swiftly changing attitudes and emotions instead of loving him as her dad. As Elaina worked to navigate her two responsibilities of managing her dad and loving him, the theme of responsibility repeatedly entered the conversation:

Oh my gosh, umm...definitely still a sense of responsibility. But in the past couple of months, since he’s been doing so well, I’ve kind of felt less pressure and that role... And

my dad has also just become, thankfully, so much more kind of capable and less on edge and needing less from us.

Consequently, Elaina described her family in unique terms that stem from the TBI-P and her experience with ambiguous loss. Forced to accept a new and ever-evolving version of her father, she viewed her role in the family as one of responsibility. To Elaina, her description of family must always include an element of responsibility and caregiving as a direct outcome of her experience.

Elaina also described herself through the lens of her experience with ambiguous loss and TBI-P. Speaking directly to her description of self, she noted:

Oh absolutely, absolutely. I think it [the surgery and subsequent challenges] changed how I value myself. So, I need to be useful in order to feel valued because there was a lot going on. It was kind of...and I'm sure you can relate to this, like selling my mom as a single mom but also, like, with a parent who is also a kid? My mom always jokes that it feels like she has three kids! Because, essentially, he [the father] is the third child in that. And so, I felt, like, as the oldest and most capable, second most capable person in the household for over a year, even though I was in fourth grade. I kind of felt...definitely the role of caregiver, a lot of responsibility. Even though I know my mom did her best to make sure us...for us to not feel that way, but there was a lot of stuff to do and definitely falling into that role. Umm, still to this day, I do feel a lot of value in feeling useful and kind of the manager of whatever job, relationship, situation I'm in. I need to feel useful and like a manager.

Elaina developed a self-image that is heavily rooted in her experience with ambiguous loss. At the core of her response, she noted that her value was formed through her experience with her

father. Without struggling through an ambiguous loss, it is plausible that her self-description would include a discussion on her familial value. Finding her value in her usefulness and utility stems directly from her processing the ambiguous loss of her father. Further, Elaina talked about herself as some kind of outsider in her own life, an interesting glimpse into how ambiguous loss has shaped her self-image:

I'm actually building better relationships with people who knew my dad before his injury and surgery from California. Because now as an adult, you know, it's easier to have these conversations. He's had a close couple of friends who knew him for the past thirty years and...I...I don't know. It's kind of like going into an investigative documentary about your own life because I'm now asking them questions I didn't know how to ask in fourth grade. So, what part of this was my dad before the surgery, and what part of this was my dad before the injury?

Here, Elaina attempted to bridge the knowledge gap in her life by trying to discover what her father was like before the surgery. Interestingly, she compared this search for truth to an investigative documentary, attempting to uncover and separate the surgery from the father; what actions or behaviors were caused by the surgery and what was her father being himself? In this quote, she is pushing back against her ambiguous loss by trying to define certain elements of it and trying to decipher her life story, which tells me that the ambiguous loss is still omnipresent in her life. However, she is now able to more fully develop a frame of reference as she is able to tease out some of the nuances of her father and the surgery, helping her process her experience.

Further, Elaina also discussed how she viewed herself through the lens of confidence. When asked to describe her life before and after the injury, she made connections with her past

and present dealings with confidence, noting she was very confident before the injury. After the surgery, a different image began to emerge:

And more, I guess, confidence? I didn't realize how much I struggled with confidence until, like honestly, the past year. So confidence was definitely...I think it had a lot...it came out as more...it would kind of swindle. I went from fourth grade, I had no confidence. I wouldn't do anything. I think I overshot into pride? Um, definitely overshot that one a lot. And then, got really humbled as soon as I graduated college! And then, I'm having to kind of rework that.

In this instance, Elaina connected her feelings of loss to her confidence level today. Moving back and forth through her perceived confidence levels as the years passed, the role of ambiguous loss in the shaping of her self-image is evident.

Finally, Elaina described her situation differently depending on the time of her life that was being referenced. As it relates to the initial head injury her father suffered before she was born, she described her life as normal since she had no way of contrasting her injured father to a non-injured father: "It's one of those things where because he, I think...one thing is he had it so long before...even before my mom knew him, technically, it's just the way things were."

Without the chance to grow up with a non-brain injured father, there was no point of reference to what would be considered a normal childhood. As an adult, Elaina was able to more fully understand her situation and even able to empathize with the issues her parents faced after the injury: "It's not even like a normal marriage issue, it's my dad had a traumatic brain injury and can no longer communicate his needs or understand and process what we need." To her, the situation evolved from one of normalcy (since there was no point of reference to suggest her childhood was any different than other children) to one of understanding and acceptance (her

situation was not a normal marriage issue faced by others, but an issue that has to deal with her father's ability to communicate and process information). In this sense, the developing view of her situation was dynamic and shifting as she learned more about her father.

### **Participant 2: Paul**

Paul was referred to participate in the study by his sister, Elaina, whose story opened this chapter. He was approximately two years younger than his sister when his father experienced his brain surgery, a left temporal lobectomy and partial removal of the hippocampus. Although close in age to his sister, their experiences growing up with a brain-injured parent were vastly different. Paul received the brunt of his father's rage and anger, and while he never experienced any physical harm at the hands of his father, the emotional carnage left in his father's wake fell solely on Paul's shoulders. In our interviews, he referenced the turmoil caused by his relationship with his father, which painted a different version of the father that Elaina referenced in her interview. Interestingly, this differential description aligns well with his sister's claim that their father was many different versions of himself over the course of his post-surgery life. As Paul poked about his experiences, his emerging feelings of ambiguous loss appeared to be much stronger than his sister's. While age and gender cannot be isolated and identified in this study as the cause of their different views of TBI-P and ambiguous loss, their experiences remain vastly different.

#### **RQ1: Influence of Ambiguous Loss**

##### ***Life Before the Surgery***

Discussing life before the surgery, Paul initially struggled to recall many details. However, he could recall some sense of happiness as a young child: "Happy, I'd say I was a kid, you know? Growing up on the lake, I enjoyed...life." As a baseline, however weak the memory,

there was a point in Paul's life where he remembered being happy with his father. Otherwise, as a young child, he did not have many memories of his father pre-surgery, only recalling that his father had different health issues over the years leading up to the surgery. Pressed to recall other memories or feelings from his childhood, Paul was able to extrapolate other details about his father: "Um, I'd say we were close, it's just hard to remember. I'd say we were closer I felt like...I do remember before, I could feel like I could tell him something." Although splintered, the image of a caring father began to emerge from Paul's descriptions and memories. To help, over the years, his mother would fill in the blanks of his childhood, offering him further insight into the seemingly healthy relationship between Paul and his father:

I don't have a lot of memory of that [before the surgery] but I do know...my mom very vividly remembers that my dad was very good with us. And I see that in the way he treats other younger kids. For whatever reason, even afterwards, he's just really good with younger kids. I'd say, like, anywhere from like, the ages of 7 and earlier, he's just really good with them.

Knowing that his father was a good dad before the surgery seemed like a distant world to Paul. However, over the years, Paul had the opportunity to watch his dad interact with other young children and found himself impressed:

With cousins and, kind of, neighbors' kids, I just know that he's really good with that. So I think he was really good, you know? There's a lot of pictures of us just having fun and whatnot, so...

As we continued the interview, Paul appeared to have been affected as he watched his father positively interact with children. Paul can remember a father who was loving and supportive before the surgery, but what about afterwards?

***Post-Surgery: “He Would Become Very Hostile”***

After Paul’s father had his surgery, their relationship soon began to suffer. While not an immediate dissolution of their relationship, Paul felt a gradual shift that intensified in speed and severity:

I wouldn’t say, like, a direct change of black and white immediately. But, I noticed over a period of time a change. Like, for me at least, our relationship had grown apart after the surgery. It wasn’t immediate, but it definitely changed over time.

The change Paul referred to would soon become apparent due to the anger and rage directed at him at the hands of his father and his inability to make sense of the ambiguous loss that he was living through. As we discussed how his father was a good father with him and his sister before the injury and good with other young kids after the injury, I pressed Paul to reflect on how that has made him feel over the years:

Yeah. There have been times when my cousins would come down and visit and he would always treat my sister and I unfairly compared to what my cousins got. It was, like, we were always held to a higher standard. I know they were guests but he would always go above and beyond to make it ridiculous. You know, it was...we were never perfect. Like, he never told us he was proud of us, but basically, family would come over and they can do basically what they want to the house, and he would be happy that they were there, so...

Here, Paul is working to reconcile the father that he knew before the surgery. After the surgery, his father emerged as an emotionally-changed man, one who was filled with anger in front of his family and the father who was totally different in front of guests in the home. Living in this type of ambiguous environment, Paul struggled to make sense of who his father really was and how to

navigate the differences he saw. Simultaneously, Paul was dealing with another more ominous issue, his father's growing rage. As we discussed this issue, one word kept recurring: hostility.

Over the course of our interview, Paul referenced the word *hostile* 12 times and it became a central talking point as we explored his feelings of ambiguous loss. After the surgery, Paul worked to come to terms with his father's rage and anger, forcing Paul to describe his post-surgery father much differently than his pre-surgery father: "He would basically become hostile, and wouldn't...he couldn't understand that he was actually doing that for a very long time." On top of having a father who was emotionally unsettled, his father also could not regulate or acknowledge that his actions were wrong. To add more stress, Paul ended up bearing the brunt of his father's anger:

But my mom always noticed...told me...so I knew it was true, but that he truly, heavily put his anger on me. I never knew why. I never why by myself but my mom always told me it was because I was just like him. And he saw his flaws in me and took them out on me because I had those flaws.

In turn, Paul was living with ambiguity and loss on multiple levels. First, he mourned the loss of his pre-surgery father and had to rework his relationship with him. Second, he was forced to deal with ambiguity of why his dad was taking his anger out on him, living in a sort of haze where he received the consequences for something he did not do. Finally, Paul began to pull away from his father, a dissolution that created ambiguous feelings and eventually, an ambiguous loss.

Exploring the concept of hostility and how it might have affected Paul, he offered more insight into how father showed hostility:

He would just get very hostile...a lot of it was like if things weren't where they should have been, he would throw things, you know? Not at anybody, but just very...rough with things.

Here, Paul is attempting to merge the two opposite images of his father: a wonderful man during his childhood to a raging man during his teenage years. To this day, Paul struggles with how to reconcile those two images:

But even...even today, there is some form of space and I really don't have interest in telling him because either the way he reacts or you know, either doesn't care or he would just react hostilely [with hostility] if I asked him if a friend could come over. He would always just be like, no. And just...I never cared to deal with that.

Consequently, Paul began to take on the hostile nature of his father and it eventually reworked his own views on life: "I felt like overall, I viewed life a little more hostile. Not...I didn't view everything as hostile but I noticed slight changes on the way I viewed things." Pressed further, Paul offered more clarification: "I'd say hostile...I guess a more realistic look you know? Accounting for those factors. Um, I guess just viewing the situation as more of a reality instead of just like, being happy all the time. You know?" The hostility offered by Paul's dad played into the ambiguous loss he experienced and left him reeling on how to merge the competing images of his father both pre-and-post surgery.

### ***Defending the Indefensible?***

Knowing that the father his mother described was not the same father that he grew up with, there was a dissonance in Paul's view of his father. So much, in fact, that it eventually shaped Paul into a sort of hybrid family member, playing protector to his father while also bearing the full force of his father's rage.

Yeah, because I never knew what he was doing was falling under what. Because I mean, and I guess I'd say I was the most...if I wasn't in the argument or whatever, I was the most sympathetic...empathetic for him because I knew where he was coming from. Him and I think a lot of the same way and I can...I can get down to his level and understand kind of where he's coming from. But I know it's to an extreme and I think I blame the extreme on the injury but the initial decision on him because I can almost picture myself making the same decision but not the same response.

Here, Paul struggled with ambiguity of the loss of his father and found himself defending the very man who continuously placed his anger and rage on him. This was an interesting finding as the ambiguity of his relationship with his father had caused him to act as both defender and victim to the same person. Delving further into his seemingly conflicting roles, the ambiguity became more evident, when Paul would reach out to his father after an emotional outburst to offer support:

And whenever...let's say he was already arguing with my sister and my mom and I could see both sides of it, I would usually agree with the other person over my dad but I could always tell where he's coming from. I would always tell him after, I would never say what he was doing was right, but I see where his logic is.

Working through the feelings of loss and mourning for a father that might not ever return to his pre-surgery self, Paul found himself in the middle of his family and his father. On one hand, he could clearly agree with his mother and sister as they argued with his father. On the other hand, he felt a sense of protectiveness over his father, working to reassure and validate his feelings in order to add some worth to his father's stance. This offered a good look into the ambiguity that

Paul faced, whereas he was caught in the middle of distancing himself from his father while still loving him and wanting to support him.

### *The End Credits*

During our interview, Paul offered a moving image of his pre-surgery relationship with his father:

Well, I guess...when I look back on that part before, I think it's just me seeing myself as a kid. Kind of, just...my backyard was a lake and there are pictures of me in the lake and in the backyard. There's one picture...I'm sitting in the backyard and my dad is sitting right next to me. And it's like, almost like the...the picture ending of a movie kind of picture. And I know it was not intentional at all, because it's my dad. And that I guess is the picture of every single time I think of before that time point of just me being happy and not really caring.

As Paul reflected on his father and their eroding relationship, he offered a fleeting and less-complicated image of life before the surgery. As he looked at the picture of himself with his dad, he was transported to a simpler time where he was allowed to experience a happy childhood. At that point, there were no major problems to trouble him and his relationship with his dad was innocent, lacking any of the emotional baggage that would soon attach to their relationship. Listening to Paul describe this picture as representing a sort of end to a movie indicated the finality he felt about their relationship since that singular point in time. Consequently, his feelings of ambiguous loss came to the forefront, forcing Paul to accept his father in many different forms, attitudes, and demeanors. Struggling to bridge the gap between his reality and his past, Paul continued to struggle with the ambiguous loss of his father. Had the damage irreparably severed any chance of a relationship between him and his father?

Over the years, Paul battled mightily with his father and worked to navigate his feelings of anger and compassion for the very man who caused him strife. Instead of walking away, Paul chose to fight as much as he could in hopes of salvaging his relationship with his father. However, even his acceptance of his ambiguous loss might not be enough to return to a sense of normalcy. In Paul's words, the relationship between them was much like a roller coaster of emotions. When asked about his relationship with his father today, Paul noted:

Much better. Well, I say better as of right now. I'd say it almost kind of was like...right after the surgery, it never went up, it just seemed like a slow decline and then really fast decline and ever since then, it has been going back up and has never been the same. And I don't think it ever will for the rest of my life between my dad and I...So I definitely think it's...it has definitely gotten better. But I don't think for the rest of my life that it will never be the same.

His description of their relational ups and downs is important in understanding the consequences of such volatile changes.

At a certain point, Paul decided that while positive changes were welcomed, the relationship might have been damaged beyond the point of any meaningful repair. There was a point, however, where Paul saw a slight shift in his father's attitude towards reconciliation and forgiveness:

But there was one point where I just know...when my mom would chew my dad out for kind of being his stubborn, you know, angry hostile self, you would just kind of...say sorry, but almost like, a definite sorry but you could almost tell he was not sorry. Just kind of like, whatever makes you happy, sorry. And one day, he really was like, hey I am genuinely sorry. I think he realized how he treated us.

Here, Paul recognized a difference in his father's attempt to repair their relationship. However, it also felt like it was too little, too late. Speaking further to his feelings, Paul painted a picture of comparison between life before and after the surgery:

But I think it was also a point in my life when you're just a kid where you don't have stress. You don't have goals in life, you just go and hang out with your friends because everything is fun. And nowadays, dealing with him is just one more thing, part of the pile. So, I don't know how...if I really...in my mind I think I don't really focus on it.

That's one more thing on the shelf to deal with.

Noticing the difference between his carefree life before the surgery and his feelings of duty after the surgery, Paul struggled to reconcile his ambiguous loss. To deal with his father and all of the emotions of the loss, Paul viewed his interactions with his father as something that had to be done out of duty, not out of genuine concern or even love. Consequently, the feelings of loss are so strong here that Paul did not know how to interact with his father in a meaningful or productive way. How can a relationship be successful while feeling that like that person is no longer emotionally or mentally present?

Paul experienced many issues in his life which can be connected to the influence of ambiguous loss. First, the dissolution of his relationship with his father is central to his experience with TBI-P and ambiguous loss. Paul was forced to readjust his expectations, attitudes, and approaches in dealing with his still-living father, causing him to mourn his father as he was before the injury. As an example, Paul explained what it was like to be around his father: "But at home, I get almost stressed to live...almost anytime it seems like, to a certain extent, if I am around him or something there is some sort of stress." Consequently, dealing with his father became more about the management of the relationship and less about the relational

strength or positive emotional possibilities of that relationship. In turn, one major influence of his ambiguous loss was the feeling of stress endured in every interaction with his father.

Secondly, Paul was treated as the primary outlet of his father's rage and anger, something that amplified the feelings of loss and distance between him and his father:

But my mom always noticed...told me...so I knew it was true, but that he truly, heavily put his anger on me. I never knew why. I never why by myself but my mom always told me it was because I was just like him. And he saw his flaws in me and took them out on me because I had those flaws.

The treatment of Paul at the hands of his father left a lasting impact in his life. During our interview, it was clear that these interactions between Paul and his father weighed heavily on him. When pressed for specific examples of his father's declining emotional state, Paul was able to offer insight into these moments:

I'd say for a long time, like I said hostile...he would...he would get very angry at something and just kind of like, focus on it...to like a crazy extent. For example, if I wouldn't pick up something, that would basically turn him into a train wreck, and he would just kind of go nuts over it and just, like, not even...it's someone you would even want to be talking to when that happens. You know, you just kind of...you want to get away.

As Paul struggled to process his feelings of loss, he was constantly working to avoid triggering his father in an attempt to avoid his anger and rage. This type of relational incompatibility has led to lasting effects in their relationship, with Paul believing that their relationship would never return to the pre-surgery baseline.

A final influence of ambiguous loss, Paul found himself conflicted on showing empathy for his father while simultaneously participating in conflict with him. Over time, the responsibility of playing peacemaker between his family and having to affirm his father's feelings left him feeling conflicted about their relationship:

Yeah, because I never knew what he was doing was falling under what because I mean, and I guess I'd say I was the most...if I wasn't in the argument or whatever, I was the most sympathetic...empathetic for him because I knew where he was coming from. Him and I think a lot of the same way and I can...I can get down to his level and understand kind of where he's coming from. But I know it's to an extreme and I think I blame the extreme on the injury but the initial decision on him because I can almost picture myself making the same decision but not the same response.

Paul struggled to make sense of his position in the family and his conflicting feelings toward his father. Eventually, Paul came to a still-occurring sense of ambiguity, blaming the initial reaction to a situation on his father, not on the brain injury or surgery. Simultaneously, Paul set a sort of limiter on the blame to be placed on his father, noting that any extreme reaction to a situation or conflict could probably be pinned on the effects of the injury or surgery. The ambiguity here is caused by Paul having to live in two different worlds, balancing his feelings and reactions to the reality of his father's injury. In this case, ambiguity served to obscure their relationship and made it unclear where Paul was supposed to stand, either on the side of his mother and sister as they banded together, or on the side of his father who had no support in his fight to be understood.

### **RQ2: Tangible Outcomes Pertaining to Ambiguous Loss**

Paul could not articulate a feeling of ambiguous loss to any tangible consequences like his sister, who would become a teacher based on her experience with TBI-P: "Yeah, I mean, I

don't think there's really been any big decisions that I've made solely based off of that."

However, as we continued talking, a couple of tangible outcomes began to emerge relating to his experience growing up with a brain-injured father and his struggle to deal with his ambiguous loss. To begin, Paul imagined himself as a future father and promised that his children would not grow up in the same type of anger-driven environment that he experienced:

...I told myself that like...I purposefully will treat my kids differently if that makes sense? You know, I think it's just something I just realized, that...I went through that. You know? I don't want my own kids to be treated that way.

It is important to note that the anger and rage Paul experienced was a result of the brain injury and not the result of a genuinely-belligerent father. In this sense, while not a currently-tangible outcome, Paul was emotionally changed by his father's injury, enough so that his future decisions are already being shaped by his experience. Instead of sorting through his situation with a focus on the negative and all that he had been through, Paul flipped the script and promised that his children would be raised differently, choosing to transform his experience for the good in his life. In place of anger, perhaps there would be patience. Instead of rage, there could be love and acceptance. The ability of Paul to create a better life for his future children is not only admirable, but impressive when considering that Paul believed he had lost his childhood through his experience with his father's injury and surgery:

I maybe lost a childhood that probably could have gone better. But I try not to sit back on it and think, you know..."man, I really wish it was the other way." You know? Like yeah I lost it, but it's the way it is.

Here, Paul acknowledges his feelings of loss; he believes he lost his childhood, which the evidence would certainly bear out. However, Paul also attempted to move on from that loss, all

in order to ensure the cycle of anger and rage does not become generational. While not directly able to connect his feelings of ambiguous loss to tangible outcomes currently in his life, Paul was able to connect his feelings of loss to his future endeavors.

### **RQ3: Descriptions of Family, Self, and Situation Related to Ambiguous Loss and TBI-P**

Paul was positioned in a unique spot in his family as it relates to Research Question 3. He was caught in the middle of agreeing with his mother and sister in arguments with his dad, but also feeling empathy towards his dad and being able to understand and appreciate his point of view. However, this neutrality did not serve him well, as his father would routinely focus his rage and anger towards Paul. While his father was never physically abusive, the emotional toll that his father left on Paul was still evident during our conversations. Consequently, an internal battle seemed to be occurring in Paul, whereas his relationship with his father was damaged almost to the point of complete disrepair. Interestingly, Paul's description of his situation did not turn exceptionally negative either.

How did Paul describe his family, self, and situation in light of his experience? First, Paul described his family in different ways depending on the time frame being referenced. Before the surgery, Paul was reminded by his mother that his father was very good with him and his sister and thus described his family in positive terms. After the surgery, the uninjured family members siloed themselves to gain strength and worked to reinforce one another in arguments and disagreements with their father, pushing Paul to describe his family relationship in more negative terms. However, Paul often found himself struggling to side solely with his mother and sister. He discussed how he approached his father: "I give him some blame, but I know it's not all his fault." As Paul got older, he began to mentally work to separate the injury from the man, trying to discover what actions or attitudes could be attributed to his father and what was caused by the

surgery. While Paul's family relationship is currently much better than before and his description of his mother and sister are positive, he still struggles with his father's past and how he was treated by him. Thus, his description of his father is different from his family.

Secondly, Paul described himself in ways that reference the struggle caused by his ambiguous loss. As we talked about how he viewed himself, Paul was quick to note that he processed what has happened in his life in different ways. Primarily, he worked to keep his experience at a distance:

I'd say I almost try to distance myself because I know it's brought on hardship in this and that and me distancing myself from it gets me away from it. But I try not to, like, forget about it. But, it's not something I want to bring up non-stop.

Internalizing his experience served Paul and allowed him to find distance and solace away from the everyday stress he experienced. By keeping his experience away, perhaps it was easier to deal with what he had been through. However, Paul also referenced the need to remember his experience while not overly relying on it to find his identity; his experience did not define him but it also did not pass by without any consequence in his life. This is interesting as Paul appreciated his experience while he simultaneously worked to keep it distant. This speaks to the high levels of ambiguity that TBI-P adolescents must navigate, and how a TBI-P event suffered during adolescence can result in changes to how they view themselves later in life. In this case, Paul viewed himself not quite as a victim but not quite as a victor either.

Finally, Paul shared his thoughts on how he viewed his situation in light of his experience with TBI-P and in context of suffering an ambiguous loss. Speaking to his situation recently, he noted that things were looking better on the relational front with his father:

I'd say we're on the up. It's one of those things where...it's...there's not a constant struggle and I think there ever won't be. It's not constant but I'd say it's...it has to do a lot with my dad just understanding. You know like, my dad wants to understand but his brain just won't let him understand things as quickly.

Even through the lifetime of pain and strife brought on by his father's anger and rage, Paul believed his situation is better now than in years past. With TBIs, it can take years for the effects to improve (if they ever do) and it can take many months or years to get the correct balance of medications to balance the changes. Perhaps enough time had passed for his father to level out a bit and for the medications to settle his father's demeanor. Whatever the reason, Paul agreed that his situation is better. However, he also acknowledged that the present situation with his dad still included plenty of challenges.

It's one of those things with him, like...you just get tired of repeating the same things. And he'll forget things, so every single time he comes home, he asks the same questions over and over again. And I don't know if he's just trying to make conversation or he really doesn't remember, but there's a lot of just, repeat questions and it gets frustrating, you know?

While these challenges might seem infantile compared to his previous dealings with his father, they remain a challenge to process and work through, something that requires a concerted effort every day on Paul's part. Paul found that his situation with his father was rough, but that it was also not without cause; Paul grew from his experience and found some sort of solace in the journey.

### **Participant 3: Robert**

Robert, the third participant in the study, was only 13 years old when his father suffered a severe TBI. In 2019, his father was returning home around 11PM from a late work meeting. In a relatively small city of less than 100,000, this trip was routine and safe, even later in the evening hours. Sitting at a red light, the turn light flipped to green and Robert's dad entered the intersection. Normally, his father checked both directions to ensure he could safely enter the intersection. This time, however, his father did not look both ways and in an instant, he was t-boned by a speeding drunk driver on the passenger side door, flipping his vehicle and landing on the roof in the oncoming traffic lanes. As it turns out, this would be the first of two crashes caused by the same drunk driver, who is currently in jail awaiting their trial; the same driver caused another wreck a couple of weeks later. Surprisingly, his father was able to extricate himself from the vehicle and after the police arrived, refused transportation to the hospital. Instead, Robert's father called home to be picked up from the scene. It would take a few weeks, but the family soon began to realize that their father was suffering from something. After a trip to the doctor, it was confirmed that his father suffered a moderate TBI in the crash based on his symptoms. Consequently, Robert's family began to experience major stress as their once-calm father became more difficult to live with.

Robert was referred for inclusion in the study through a support group. Robert's mother loved the idea of him participating because she felt that he needed some way to get his feelings into the world. According to his mother, Robert tended to internalize his feelings and act as if his father's injury did not affect him. As we explored his experience with his father's injury, his unwillingness to go beyond the surface of his feelings was evident. In turn, it was difficult to gauge how ambiguous loss might have affected him. However, his unwillingness to discuss many aspects of the TBI-P event in depth offered convincing evidence that he was suffering

from an ambiguous loss and that he might not be able to vocalize his feelings at this point in his life; not enough time has passed since the injury for Robert to process, adjust, and reflect on the injury.

### **RQ1: Influence of Ambiguous Loss**

#### ***Pre-Injury: A Normal Dad***

Before his father's injury, Robert was not able to recall or share much about his father and their relationship. However, he shared just enough to get a general idea of his father before the accident. First, his father was described as the breadwinner of the house, in opposition to his mother who stayed home. Robert also described his father as a steady person, which contrasted to his father post-injury: "Like, steady. Not rapidly changing like he was after." It was interesting that Robert chose the word "steady," which indicated that his father was emotionally unsteady after the injury, something we would talk about later in the interview. Since Robert's father was considered the leader of the household, Robert's description of his father could be understood to mean that his father was a normal one. Beyond the emotional changes his father experienced, Robert remembered that his father was more active before the injury: "Yeah, like basketball, biking, sports..." To this point, we had established that his father was a steady leader of the house and that he was active with his children. Robert was also able to share that his dad was once more precise with his time management and adhered to strict timeframes: "And then, whenever he was in town, we'd have like...very exact deadlines for going places. And now we just say, next week we're going to go whenever." As we continued discussing what Robert recalled about the night his father was injured, he was again not able to recall much: "I don't know, because it was 11:30 at night before school and I think I was just watching a movie. And I was like, what? He just got in a car accident?" When pressed further, Robert admitted that he

was surprised at the news since they lived in a relatively small town: “I don’t know, it’s just...there are never really any people out at 11:30 here, so...” Beyond these simple descriptions, Robert would not share more details about his pre-injury life with his father.

### ***Post-Injury: Shifting Landscapes***

As the interview opened, Robert appeared disinterested in sharing much information about his experience. Upon further exploration of his father’s injury, he also seemed unaware about the severity of the injury. While he could not specifically point to the injury’s severity, he made a statement regarding the initial changes he noticed in his father’s attitude and behavior. When asked how he knew his father was badly injured, he responded: “Uh, I don’t know much about those details. It was really bad, I guess.” As we explored what he meant by “really bad,” he continued to share: “Uh, just how much changed, in like, a matter of days.” At this point in the story, it did not appear that his father had gone to the doctor immediately and that Robert was basing his guess on the severity of his father’s TBI based on how his father began to act. Pushing forward, Robert was asked what he meant by the word “changed” in his previous answer, to which he replied: “Like, personality and emotions.”

Eventually, Robert shared that his father started to experience quick personality changes after the brain injury. While his dad seemed to be more relaxed about certain things, he also noticed his dad experience “...quick personality changes.” These personality changes were noticeable to Robert and complicated his view of his father, offering a contrast to how his father acted before the injury. Robert later described his father as rapidly changing, noting: “Like, in like 10 minutes, it will go from, like, happy to angry.” These quick changes in his father’s emotional state left Robert perplexed as he worked to navigate his relationship with his father, noted here in his attempt to describe his father: “Yeah. I don’t know how to explain it, but he

was. Like temper and stuff. And attention, like...he'd spend two hours on things, now it's like five minutes." It is possible that Robert had experienced an ambiguous loss of his father but could not articulate it.

### *Avoidance or Acceptance?*

As one of the most challenging interviews in this research project, it was unclear whether Robert was avoiding his feelings of loss or if he had already accepted what had happened to his father. As we explored how Robert was currently feeling about his father's injury, he shared: "It feels like, normal in a way...I think we just adapted into it and like, it's like more of our everyday life." In a sense, it appeared that Robert had simply accepted his father's injury and had embraced his new sense of normal. He spoke of how his family adapted to the injury and worked to accept the different father who emerged afterwards, speaking to their attempts to embrace his father. At other times, Robert spoke about the time that had passed since the injury and how that time might have helped normalize the experience: "I think it's just been like...it's been like two years since the accident and I think I've just gotten older." When we explored his feelings further, he continued: "It's just like...I don't know. It [the brain injury] wasn't surprising anymore." This was interesting as he had only expressed surprise at the initial injury, not the brain injury. At another point in the conversation, Robert shared that the changes they experienced did not affect him, only that his family was going through a "big change." These contradictory statements provided evidence that Robert had not fully acknowledged what had happened to his father, a hunch that was confirmed in debriefing with his mother, who shared: "Robert holds stuff in and will not let on that he's struggling with it." Perhaps this emotional fortitude is what kept Robert from sharing his true feelings on his situation.

In Robert's case, the influence of ambiguous loss is twofold. First, I do believe that Robert suffered an ambiguous loss and that it has kept him from sharing his thoughts and feelings. In this sense, the loss was either too painful to think about and vocalize or not enough time had passed since the injury for the ambiguous loss to have any appreciable effects as seen in older participants. Secondly, Robert did share that he had experienced a change because of his dad's injury, his growing sensitivity to those around him. When pressed to expand on his growing sense of sensitivity, he responded: "Like, normal things...some are more tough than others." In his view, he had noticed that he became more sensitive to things or situations in his life, noticing that some situations were more tough than others. This type of thinking by Robert alluded to the possibility that the ambiguous loss he experienced did have a small influence on his life at the time of this interview. As time passes, will there be more influences that emerge from his ambiguous loss? Possibly. However, Robert was only able to vocalize his sensitivity as the only influence of ambiguous loss.

### **RQ2: Tangible Outcomes Pertaining to Ambiguous Loss**

While Robert was not able to share how he had experienced many tangible outcomes this soon after his father's injury, he had experienced the loss of his father in one sense. For instance, before the injury, his father was much more active with him, with Robert noting that his father used to play outside with him more often. However, after the injury, his father's diminished physical capabilities left Robert without his father's active involvement in his life. Therefore, one tangible outcome is that Robert lost a sense of closeness with his father because of the injury. Over time, this lack of engagement could lead to other tangible outcomes such as feelings of disassociation with his father.

Robert definitely suffered an ambiguous loss. However, the effect that it might have on him in the future is yet to be seen. As Robert worked to keep his feelings and thoughts internalized, it was clear that he was feeling some negative thoughts about his father's injury and post-injury emotional changes. At his age, it might be that not enough time has passed for any tangible outcomes to present themselves fully. Alternatively, Robert might not have been as forthcoming due to his position in the family as the oldest child. He might have seen himself as the older brother and one of the family leaders in his father's emotional absence. Consequently, he might have felt the need to keep his emotions in check during our conversation and to not let on to his true thoughts on the situation.

### **RQ3: Descriptions of Family, Self, and Situation Related to Ambiguous Loss and TBI-P**

Robert was more open when it came to discussing his relationship with his family, especially his mother. Robert sees his mother as "a lot more fiery and fierce now" in the time since his father's injury. When pressed to elaborate, he was only able to vocalize that her demeanor had changed in most of the interactions he witnessed and that she used to be more "chill" in her actions. This could be the result of the family dynamic that shifted after the accident. Earlier in the interview, Robert noted that his mother was now employed and gone to work during the week and his father stayed home, unable to work. This flip in roles is the opposite of their pre-injury life, which could be causing his mother to act differently than before the injury. In this case, his mother is serving as the sole breadwinner and would understandably be under a lot of stress in her redefined role. Robert went on to describe his mother as "much more serious," which would also make sense given her new role in the family. To Robert, his mother had experienced a major shift and he had noticed. It is unclear if the change Robert experienced in his mother will have a lasting effect on him. However, Robert's view of his

parents is that his dad has physically and emotionally changed since before the injury and that his mom has turned much more serious.

Robert also briefly discussed his relationship with his siblings, which produced another finding. When asked if he talked to his siblings about the injury and the changes his dad had experienced, he noted that they did not talk about the injury. Later in the interview, Robert stated that his life had improved since the injury, even though he had not discussed his or his family's feelings: "It's just like a closer family." As Robert kept his feelings inside since the injury, it was telling that he felt closer to his family even though he was emotionally unavailable to express his feelings. He went on to note that his siblings were closer to him than before the injury, mostly based on the fact that they were spending more time together because of the injury: "I think there is babysitting more often, like having appointments and stuff." Here, the injury had caused Robert to be more responsible for his siblings and to care for them while his parents attended appointments and other injury-related meetings. In this case, the closeness felt by Robert was not an emotional closeness, but a non-emotional closeness forced by the injury. Robert was spending more time with his siblings because he had to, not because he necessarily needed an emotional outlet. This is not to say that Robert is not close to his siblings as he most likely cares about them. However, he was being asked to grow up faster than normal and to take on responsibilities that would normally fall to his mother.

Robert did not offer much insight to how he viewed himself or his situation in light of his experience with ambiguous loss. Beyond discussing his growing emotional sensitivity to situations, he claimed that everything else was basically the same as it was before the injury. However, he was able to vocalize that the injury was more difficult to deal with when it first occurred: "At the start it was harder, but it's pretty easy now." These contradictory statements

lead me to believe that Robert might not have been as truthful about his experience with his father. It is important to note here that during our interview, I could hear Robert's father in the background as he talked and moved past the camera, just out of view; Robert would often look up and off camera during our interview. His father would often stick his head into the room and talk to Robert, talk loudly in the background, or make noise that caused a bit of a distraction and lack of concentration on Robert's end. Unfortunately, because his father was close by, Robert was not able to communicate his true feelings. Consequently, Robert answered in ways that reduced the risk of his father overhearing him, such as answering in short sentences or single words.

#### **Participant 4: April**

April, sister of Robert, was 12 years old when her father suffered a TBI after being hit by a drunk driver. April was able to recall the accident and how she found out about it, offering insight into what happened that night:

Well, I remember my dad said that he was coming from a work meeting and then he was at the stoplight thing...And then, he usually looked before he went to be safe, but he didn't that time. Then the car hit him...There was a fast car, I think drunk driver...but I don't know. And then, the car came as my dad was going forward, and hit my dad...my dad's car, on the side of the car. I don't think it was on the side of the car my dad was on, because he hit his head on the seatbelt...like the top of the seatbelt thing. And then...I don't know what happened when the police or whoever came. I didn't hear much later after it happened.

Being hit by a drunk driver and sustaining a TBI can result in serious consequences.

Interestingly, April recalled how her dad did not seek medical attention after the accident:

He was home that night, he just came home I think. My mom went to get him and he came home. He didn't want to deal with having to go the hospital because he was tired and was just driving late at night to get home from the work meeting.

Whether her father was suffering from shock or some sort of delayed response to the trauma, her father refused to go to the hospital. However, after the accident, April began to notice some negative changes in her father. In turn, she seemed to be experiencing an ambiguous loss, even at her young age.

### **RQ1: Influence of Ambiguous Loss**

#### ***Before the Injury: "We Were Pretty Normal"***

April described her family life before the surgery as a sort of normal existence: "I guess we were pretty normal." While the definition of a standard family life differs depending on the circumstances and family structure, April noted that it was normal and that they "had a closer relationship with our mother because we weren't with dad as much." Before the injury, their father would work during the day while their mother stayed at home with April and her siblings. According to their mother, their father would often travel for extended periods too. Further exploring her life before the injury, April noted: "I was more childish I guess, I wasn't as serious about things." While I assumed that the seriousness might have resulted from her father's TBI and the associated changes the family experienced from the injury, April believed differently. When asked where the seriousness came from, she responded: "Probably age. I wouldn't say it has anything to do about the brain injury, actually. Because I actually was younger so that makes sense." To April, her seriousness stemmed from her growing maturity as she entered her teenage years and nothing to do with the injury. Finally, April described her life before the surgery as being more orderly: "Before the injury, my life was pretty organized and I knew what would

happen each day. I knew what we were doing I guess.” Aligning with what her brother had shared, their family was organized and time-structured before the injury. However, once the injury occurred and associated effects began to emerge, the image of a solid family unit began to weaken.

### *After the Injury: Positive Outcomes?*

Identical to her brother’s interview, April had to contend with her father entering the room or walking past her, speaking loudly and interrupting her train of thought. At one point, her father yelled: “Tell him I had a compromised brain injury!” I then had to repeat and rephrase the previous question as April had lost her train of thought. Unfortunately, interviewing participants in these settings is never ideal as they might feel that they cannot fully share their true feelings and experiences. However, I pressed on with the interview in hopes of uncovering whether April had experienced an ambiguous loss. After the injury, April spoke of a different life than the one they had before. First, she noted that her father was not as serious as before the injury, which to her, produced an interesting outcome: “I guess it was kind of more fun because dad wasn’t as serious about things... We would just go out and have fun some days.” As a consequence of the injury, her father was less stringent when it came to structure and timeliness, perhaps resulting in a less tightly-wound father who appeared to be more fun to April. Beyond her father being less serious after the surgery, April also noticed changes in her family’s communication with him: “Well, I guess conversations would get pretty confusing sometimes, because my dad would probably forget something, and be like what? And then, have to go back and explain it again.” While not indicative of any kind of loss, over time these changes could lead to a degradation of their relationship as the stress from the changes continues to mount.

April shared that she felt more stressed since the injury but attributed that stress to entering middle school and having new responsibilities: “Um, probably more stressed because I am going to middle school and I have new stuff...” Interestingly, her entry into middle school and her growing sense of maturity weighed more heavily on her than her father’s brain injury. Speaking to her stress level in relation to the brain injury, she shared: “...but with the brain injury, everything is chill. We have to take time to figure everything out, so it’s not as stressful.” Here, it sounds like the family, specifically her mother, had worked to keep their home life as normal and calm as possible, perhaps lowering the stress level. By slowing things down for her father and working through issues with him, the adversarial relationship often seen in head-injured patients and their families seems to be minimized here. Thus, feeling less stressed about the injury could be attributed to a purposeful plan of family action that demanded slower interactions between family members and the practicing of patience within the family as they interacted with the father.

April represents a unique participant as she situated her experience with TBI-P and ambiguous loss as a positive, working to find the good in a bad situation. Instead of wallowing in her loss, she seemed to have chosen to embrace it and found the positive outcomes in it. However, I still believe that April suffered an ambiguous loss as she is caught in between coping with her father’s changes and adjusting to them, no matter if she chose to find the good in them. In this sense, she could still experience the positive outcomes of the injury while still struggling with a sense of loss. Speaking to her family life now, she noted: “Um, I guess we’re just close as a family now.” In one sense, it seemed that the injury had strengthened their relationship, especially since she was able to see her father more often as he was no longer working outside the house. In this sense, it is appropriate that April would consider her family closer now than

before the injury, assuming that more time spent together would strengthen the bond between father and daughter. Here, one influence of her experience with ambiguous loss is that her family bonded more closely together, at least in her eyes.

Exploring this finding more in-depth, April shared that her life had gotten better since the injury, mostly due to her personal growth as she entered her teenage years: “Um, probably because I am more mature now and probably because I can understand what not to say before I say it.” Her experience with the injury left her with a greater sense of responsibility, requiring her to be more conscious about what she says before she says it. When I asked if she meant saying things to her parents, she elaborated: “Like, just rude things. To anyone.” From her response, it can be inferred that because of her father’s injury, she adjusted her communication with him and has learned what topics, attitudes, or tones to take with him. Subsequently, another influence of ambiguous loss is that April is much more cognizant of the power of her words, whether with her family or with other people. While April might have experienced some positive outcomes as they relate to family closeness and positive communication, she was still influenced by ambiguous loss. Interestingly, in April’s case, ambiguous loss might not always be a negative outcome. Alternatively, some adolescents might be able to take their experience with ambiguous loss and form it into positive outcomes. However, whether these positive outcomes hold over the long-term is unclear.

### **RQ2: Tangible Outcomes Pertaining to Ambiguous Loss**

Relating to long-term outcomes, this research study has found that ambiguous loss can result in tangible consequences later in life. For instance, when interviewing adults who experienced a TBI-P event in their adolescence, there was evidence of tangible outcomes pertaining to ambiguous loss. However, since April’s experience with the injury is so recent, it is

unclear whether her short-term positive outcomes will remain positive or if she will experience any negative outcomes later in life. At the time of this interview, April noted that her life was better since the injury, centered around her chance to spend more time with her father.

Beyond spending more time with her father, April could not speak to any other tangible outcomes stemming from her father's injury. Consequently, there are three reasons that April had not experienced any tangible outcomes pertaining to the injury. First, while April experienced changes and suffered a loss, not enough time had passed since the injury and her participation in the study to see any of those outcomes. With the passing of time and compilation of stressors on her father and the family, there is a chance she could see tangible outcomes. Second, the ability of April to remain positive and see the positivity in her situation helped to mitigate any negative outcomes that might have shown themselves by this point in her TBI-P experience. To April, seeing the good in her situation was a way to cope with changes she had seen. Finally, April's young age might have prevented her from having any longitudinal reference to how the injury might have affected her. It would be interesting to revisit April in her late teens or college years to discuss how the injury had or had not shaped her life in some way.

### **RQ3: Descriptions of Family, Self, and Situation Related to Ambiguous Loss and TBI-P**

April described her family in positive terms after the injury, noting that her family seemed closer together now than before. While this can be attributed to her father staying at home full-time and no longer traveling for work, the way April framed her response was intriguing. The family seemed closer than before, but was her assessment of a better family life based solely on the amount of time her father was at home? In this sense, the family would seem closer if the only qualifier was time spent at home, a good benefit of her father's injury. In her eyes, having her father at home allowed her to be around him more, something that she had not

experienced during the pre-injury days. In April's view, she found that having her father around was a good change: "Oh yeah, it was I don't know...I guess it was kind of more fun because dad wasn't as serious about things." Here, she spoke about the contrast between her father before and after the surgery, noting that he became less serious and more fun afterwards. For April, her description of her family resides solely in the positive, choosing to make the best out of her changing family dynamic.

In the same vein, April noted that her experience personally affected her but not in a major way: "...but, like, not in a big way...I guess it affected how I ask questions or who I ask questions to in my family. Like, going to friends, I'd probably ask my mom." While April was not able to describe herself in a meaningful way in light of her experience, she shared that her approach to asking questions shifted after the injury. I inferred this to mean that she could not ask her dad certain questions and worked to find others to ask, an indication that there might have been struggles at home that she was not able or willing to share during our interview, a hunch that was confirmed in my conversation with her younger sister (Participant 5). Beyond this, April described herself as a normal preteen, noting her growing maturity as part of the growing up process. April did not find her identity in her TBI-P experience, and consequently, her description of her situation did not tie in that experience either.

### **Participant 5: Maggie**

The final participant in the research study, Maggie, was the younger sister of both Robert and April, only seven years old at the time of the interview and five years old when her father suffered a TBI. Her siblings Robert and April had already shared details about the accident, the focus was centered on Maggie's experience with her father. As the youngest participant in the study, I was excited to interview Maggie as children of her age are less reserved in sharing

details about their lives. However, it is important to note that while Maggie was open about her experience, her sister April sat with her during the interview, which could have reduced the amount of information shared by Maggie. Regardless, Maggie was a very confident seven year old and articulate beyond her years while sharing her experience with me. At the same time, because of her young age, the interview was much shorter than her siblings and the findings were more limited.

As we talked about how she felt after her dad suffered his TBI caused by a drunk driver, Maggie shared: “I thought that it was sad for my dad because he started to show different signs of stuff that he didn’t do when he didn’t have his brain injury.” This response caught my attention since her siblings had shared that their dad had remained mostly the same, aside from being home more and having limited emotional and physical changes. When I asked what her father did differently, Maggie continued: “Well he started to fight with my mom more often and a month ago, they...my dad stopped for a while and then this month they started again.” Here, Maggie confirmed my suspicion that more changes were happening at home than either of her siblings let on during my interviews with them, as neither of them mentioned their parents were arguing. This was an interesting turn of events as it confirmed what research has told us regarding parental stress and traumatic events: parents’ stress levels rise with a traumatic event and that can lead to arguments and marital distress. Even at her young age, Maggie felt emotions of sadness for her father, who had changed after the injury. Already, Maggie had experienced a sense of loss as her father had changed into someone different than before the surgery.

### **RQ1: Influence of Ambiguous Loss**

Similar to her siblings, it is possible that Maggie experienced an ambiguous loss based on the changes she experienced in her life. First, she noticed that her parents were arguing more

often, something that was not present before the injury. While arguing parents are not enough to claim that she experienced an ambiguous loss, other changes in her life might illuminate the ambiguous loss. For example, Maggie noted that even though her father was home more, she did not see him that often, instead relying on babysitters to provide her with supervision; before the injury, with her mom a stay-at-home mom, Maggie did not have a babysitter. While a seemingly small change in her life, her decision to share this with me alerted me that it was a meaningful change in her life. Consequently, Maggie did not echo her siblings' feelings that the family was closer because of the injury, but noted that she was spending less time with them. Perhaps a product of her age and being the youngest member of the family, Maggie experienced an ambiguous loss much differently than her siblings and the influence of ambiguous loss was more pronounced than her older siblings. To Maggie, life was not improved or better sense the injury, but negatively different.

### **RQ2: Tangible Outcomes Pertaining to Ambiguous Loss**

At seven years old, no determination could be made as to the effects of the ambiguous loss on Maggie's life. While it is possible that the changes Maggie experienced will eventually lead to more noticeable tangible outcomes in her emotions, behaviors, or sense of self, there is no way to confidently claim such beliefs in this study. Instead, based on her responses to my questions, it appears that there are two major tangible outcomes in her life at this point. First, Maggie had been exposed to her parents' increasingly stressful relationship, enough so that it was the first thing she brought up in the interview. This exposure is tangible in that she had noticed the shift in her parents' relationship and she was aware of the stress it was causing to the family. Secondly, she had lost quality time with her family that was present before the injury. Before the injury, her mother stayed home with her and her siblings while her father traveled for

work, which meant that she had more attention placed on her before the injury. Thus, another tangible outcome, loss of family cohesion, must be considered longitudinally. Will this loss of cohesion prove a permanent change? If so, will this loss enhance her feelings of loss? Possibly. However, without the benefit of a longitudinal study and a chance to visit again with Maggie, it is simply an educated guess as to how her experience with ambiguous loss might stay with her as she gets older.

### **RQ3: Descriptions of Family, Self, and Situation Related to Ambiguous Loss and TBI-P**

Maggie described her family differently than her siblings, noting the struggles she mentioned earlier in the interview: her parents were arguing more and she was spending less time with them. Although struggling to deal with her growing sense of loss, Maggie mentioned that her father had been acting in more positive ways compared to immediately after the injury: “He’s been...acting a lot better than he’s been before.” On an interesting note, she also shared that her father had been helped through the medical attention he had been receiving post-injury: “Like, he started getting more time with us because of all the good treatment he’s been getting.” This told me that her father was beginning to settle the emotionally volatile struggles and returning to some sense of pre-injury normalcy. Consequently, her father was spending more time with them and less time on treatments or appointments that pulled him away from the family. In this sense, Maggie viewed her family as different than before the injury, with the negative outcomes beginning to soften. Her family was getting better, although it might not return to the baseline where they started.

Maggie noted a few changes to her family since the injury but did not speak much about herself or her situation in context of the injury; this could be attributed to her young age and emotional immaturity. The only reference she made to herself centered around her school

performance and her friends, two of the most important areas of her life at her age and outside the family. Academically, Maggie shared that she liked reading class, enjoyed math, but disliked science. Speaking to her friends, she described a couple of her closest friends but could not recall whether she had experienced any relational changes with others after the injury occurred. It is likely that Maggie held a positive self-view and that her father's injury had not affected that view, due to her age. Being so young, her attention was placed on other things in her life and she was not focused on how her experience with TBI-P might define her or affect her later in life.

### **Summary**

Each participant in the study experienced ambiguous loss in different ways. While some participants worked to normalize their experience and adjust their expectations of their injured father, others worked to minimize the impact that the TBI-P event had and concealed their emotions behind a wall of confidence. No matter the approach, several themes emerged across all five cases. First, participants lost a sense of their innocence. Whether it was Elaina being forced to grow up at an early age and working to protect her brother or Maggie being exposed to parental stress, participants lost some semblance of innocence through the injuries their fathers experienced. However, the loss of innocence was not seen as clearly in younger participants, perhaps indicating that time is an important factor for experiencing negative outcomes from a TBI-P event. For example, the youngest participant, Maggie, might not have lost her innocence at the time of the research. However, Maggie noted that her parents were arguing more since the injury, indicating that the process might have already begun.

Second, the theme of struggle was spread across the cases. However, the struggles experienced by each participant were vastly different. In Robert's case, he struggled to open up about his experience with his father, instead choosing to bury his feelings and refusing to

acknowledge his experience. Alternatively, Paul had been dealing with his father's anger and rage for many years, attempting to reconcile his father's actions and his own feelings toward his father. For Elaina, she struggled on how to protect her younger brother while processing her own feelings of grief and loss. In contrast, April attempted to live her life as if nothing had happened and did not seem severely affected by her experience to date. Throughout each story, participants were struggling in some manner as it related to the injury and their experience. However, the manner in which they struggled did not directly relate to the head injury.

Finally, the theme of resilience was found across the participants' stories. No matter the struggle or how bad their situations, participants tended to find the good in their situations, no matter how small it was. For April, her family seemed closer since the injury as her dad was home more often than her mom and the family seemed to have figured out a new normal, at least in the eyes of her and her siblings. For her brother Robert, he felt that having his dad home changed things but that those changes were not necessarily negative. Alternatively, Elaina found solace in that her father had permanently changed. While she struggled with his behavior and actions, she recently witnessed a change that has allowed her father to be a part of her life in a healthy and normal way. For her brother Paul, the years of struggle had forced him to appreciate his father for who he was, with all the negative parts included. Ultimately, all participants experienced an ambiguous loss. However, each participant framed and responded to that loss in different ways. Table 1.1 summarizes participants' responses in relation to the research questions. The next chapter discusses the findings more in depth.

**Table 1.1***Participant Responses in Relation to Research Questions*

Participant	RQ1- Influence of ambiguous loss	RQ2- Tangible Outcomes	RQ3- Descriptions of family, self, and situation
Elaina	Family role changed to protector, loss of childhood	Profession and decision-making	Descriptions were affected by her experience
Paul	Dissolution of relationship with father	How he intends to raise his future children	Isolated himself from his experience
Robert	Internalized feelings	Loss of active father	Descriptions not affected by his experience
April	Positioned the TBI-P as a positive change	Spending more time with her father	Positive descriptions of family since the injury
Maggie	Recognized parental distress from the TBI-P	Change in family dynamic and increased parental stress	Family description changed immediately after injury

## CHAPTER 5: DISCUSSION

The purpose of this study was to examine the influence of ambiguous loss on adolescents who experienced a TBI-P while living at home. The following research questions guided this study:

Research Question 1: As it pertains to TBI-P, what is the influence of ambiguous loss when experienced during adolescence?

Research Question 2: When TBI-P is experienced in adolescence, how does the perception of ambiguous loss result in tangible consequences later in life?

Research Question 3: In what ways do adolescents experiencing ambiguous loss from TBI-P describe their family, self, and situation?

Using an interpretative phenomenological analysis approach, I worked to remain in a continuous act of interpretation, choosing to avoid rigidity and conceptualization and to focus more on the lived experiences of my participants. Through this approach, I was able to fluidly entertain emerging themes and findings throughout the entire data analysis process and let the data lead the study.

Through the literature review, I discussed research in areas such as stress, PTSD, family system effects, and ambiguous loss. Researchers have long-known that in response to traumatic events, adolescents have been shown to exhibit symptoms of stress. In turn, adolescents cope by using different mechanisms, both positive and negative. However, if the stress from a traumatic experience is too great, adolescents have been shown to be susceptible to symptoms of PTSD, even if they did not actually see or experience their parent's injury first-hand. Because of the injury and the negative effects it can produce for the family of the injured person, the entire family unit can be taxed and placed under tremendous pressure. Consequently, the degradation

of the family unit can be a source of contention for the primary caregiver, the injured person, and the adolescents in the home. In turn, because of the shift in family dynamics and responsibilities, adolescents can experience an ambiguous loss. With an ambiguous loss, adolescents are not able to properly mourn the loss of their old parent but instead must continuously mourn the parent they used to know. With the inability to experience closure, adolescents are then caught in an endless loop of mourning and acceptance, whereas they are required to adjust their expectations of their injured and ever-changing injured parent.

This research has fit in with the existing literature in numerous ways. First, stress from traumatic experiences has been shown to have consequences later in life (Bruin, Sieh, Zijlstra, & Meijer, 2018), with time playing a pivotal role in determining how severe stress could be. While the existing literature has acknowledged the role that childhood stress has, this study has pushed the field forward by acknowledging the unique stress that is created through a cyclical process like ambiguous loss. Second, this study has shown that family system effects can be detrimental to the equilibrium of the family unit, forcing family members to redefine their roles in the family structure (Keiffer-Kristensen & Teasdale, 2012). While researchers have been aware that stress can lead to the degradation of the nuclear family unit, this study took a unique perspective and investigated how a TBI-P particularly affects adolescents in the home. This perspective fits in with the existing literature while simultaneously expanding the scope of knowledge in the field. Finally, this study has shown that ambiguous loss can be a powerful determinant for a happy childhood in some cases, a finding that has never been shown in a research study. Third, as it relates to PTSD, this study found agreement with the findings of Kieffer-Kristensen and colleagues (2011) where participants experienced reduced parental attention post-injury, parental marriage strain due to the injury, and daily life changes caused by the injury. This study has

shown that participants experienced all of these concerns. Finally, ambiguous loss research is severely understudied and this project serves to extend the research started by Boss (1991) and help to fill in the gap in knowledge.

### **Summary of Findings/Results**

This study contributes to current knowledge in the field by providing empirical evidence about how a TBI-P event intersects with the concept of ambiguous loss. Boss (1991) was the first researcher to coin the term “ambiguous loss.” However, her research only focused on the effects of ambiguous loss as they pertained to the primary spouse caretaker. Further, Boss (1991) took a broad approach to the concept, including different kinds of traumatic injuries and not specifically focusing on TBIs. These injuries are positioned differently than other traumatic parental events, such as parental cancer, in that other events generally have an end. For example, parental cancer can end in remission, death, or recurrence while non-fatal TBIs have recurring challenges that remain for the remainder of the parent’s lifetime. In this way, TBIs challenge adolescents in ways that other traumatic events do not. Even though Boss’ (1991) discovery of ambiguous loss was relatively recent, the concept was left mostly untouched in the years after her initial publication. Consequently, this study was one of the first to focus specifically on TBIs/TBI-Ps and ambiguous loss, positioning this research to make a contribution to the larger field of traumatic brain injuries and adolescent response-to-trauma research.

#### **Finding One: TBI-P Adolescents Can Experience Feelings of Ambiguous Loss**

The primary finding of this research study was that adolescents who experience a TBI-P event can experience feelings of ambiguous loss. As Boss (1991) only studied primary caregivers and families as a whole, this finding adds to the knowledge-base of the field as it relates specifically to adolescents and ambiguous loss. Elaina and Paul, the only two adults in the study,

experienced ambiguous loss as they dealt with their father and the negative changes he experienced after his surgery. Aligning with previous research (Ponsford & Schonberger, 2010; Thomsen, 1984; Teasdale & Engberg, 2005a), neither of them experienced a sense of closure after the injury and they had to deal with their father's major personality changes. For Elaina, she felt the ambiguous loss as a sense of grief, feeling like she had lost something but was not sure exactly how to quantify it: "Like, it did feel like I was grieving something." This feeling of grief directly relates to the literature review, where Gergen (2006) and Boss (2006) noted that "the ambiguity ruptures the meaning of loss, so people are frozen in both coping and grieving." Here, Elaina was simultaneously coping and grieving, producing feelings of ambiguous loss. She lived between coping with the stress that she experienced from the surgery and grieving the loss of a father and unstable family dynamic.

For Elaina's brother, Paul, the ambiguous loss he experienced was felt differently. As Paul witnessed the dissolution of his relationship with his father and became the primary focus of his father's rage and anger, the ambiguous loss he experienced was much more pronounced, resulting in far deeper relational issues with his father: "But even...even today, there is some form of space..." The damage to their relationship started during Paul's childhood and continued into the present day, creating a sense of loss. Paul spoke about his loss, stating that he felt that he lost his childhood. While the loss of a childhood is not ambiguous, that particular loss led to feelings of ambiguous loss. The loss Paul experienced aligns with previous research noted in the literature review, where Muir and Haffey (1984) found that when an injured parent might not return to their preinjury capabilities or personality, a loss is created. In this case, the ambiguous loss created a sense of space between Paul and his father, so much so that Paul did not believe their relationship could be repaired:

And I don't think it [their relationship] ever will for the rest of my life between my dad and I...So I definitely think it's...it has definitely gotten better. But I don't think for the rest of my life that it will never be the same.

Paul had experienced major upheaval in his relationship with his father, leading to the conclusion that he suffered an ambiguous loss.

The three children in the study, Robert, April, and Maggie, also experienced an ambiguous loss, albeit at less severe and intense levels compared to the adult participants. Since their father's injury occurred more recently, less than three years ago, the feelings of ambiguous loss were just starting to appear. For Robert, he noticed his father had changed and that he was much more emotionally volatile. However, instead of acknowledging his feelings of loss, he internalized them, offering conflicting statements on how he viewed his father's TBI: "It's just like...I don't know. It [the brain injury] wasn't surprising anymore." Later in the interview, Robert shared that the changes they experienced did not affect him, only that his family was going through a "big change." However, after debriefing with Robert's mother, she confirmed that Robert internalized his feelings and that he was actually struggling with the injury and the changes it caused. This aligns with previous literature on how families process a non-fatal loss in that the grieving process follows closely with how one would grieve a death (Muir & Haffey, 1984). Consequently, Robert chose to internalize his feelings, leading me to believe that he suffered from an ambiguous loss that could not be vocalized. Further, Robert's statements about his father changing emotionally speak to the feelings of loss, as these behaviors were not present before the injury occurred.

For April, Robert's younger sister and the middle child in the family, she offered a unique perspective to her experience. Choosing to view her experience as a positive one, she

chose to embrace it and shared the good changes she experienced. However, since the concept of ambiguous loss positions the person in between coping and grieving, by definition, she suffered from an ambiguous loss. Even though she experienced positive outcomes like spending more time with her family and a feeling a sense of closeness with them, April was affected by her father's injury, noting how her communication changed after the injury: "...but like not in a big way [when asked if things changed]...I guess it affected how I ask questions or who I ask questions to in my family." While her sense of ambiguous loss was weak and seemingly insignificant, she could have been battling her feelings of loss through positive framing of her situation; April was able to use her positivity to mitigate any negative outcomes. It is also possible that her young age prevented her from engaging in longitudinal comparisons to her previous life as not enough time had passed since the injury to determine if any negative outcomes would occur. Alternatively, although she experienced an ambiguous loss, it could be that such a loss does not always have to lead to a negative outcome. In this view, some adolescents might be able to take their experience with ambiguous loss and form it into positive outcomes. However, whether these positive outcomes persist over the long-term is unclear and provides an opportunity for future research.

Maggie, the final participant in the study, was the younger sibling of Robert and April. Although she was only seven years old at the time of the study, she was able to illuminate changes that were happening at home that neither of her siblings had mentioned, including the fact that her parents were not getting along: "Well he started to fight with my mom more often and a month ago, they...my dad stopped for a while and then this month they started again." While researchers have long been aware that a traumatic event can lead to parental arguments and marital distress, it was interesting that this was one of the first things we discussed in

Maggie's interview. In addition to seeing her parent's relationship begin to show signs of decay, Maggie took a different stance on how her life had been affected by her father's injury. Maggie believed that her life had not improved since the injury and that perspective differed from her siblings' belief that it had gotten better. However, she also noted that her father had been improving his behavior recently, stating that "he's been...acting a lot better than he's been before." As a result, it appeared that Maggie was also caught between coping with her father's injury and grieving the changes that she saw in him and within her family. This led me to believe that, although faint, she had experienced an ambiguous loss. Whether this loss strengthens over the following years is unknown.

Across all participants, ambiguous loss could be seen in varying degrees. While older participants experienced ambiguous loss more strongly, younger participants had the benefit of time and had not seen major changes, producing a weaker correlation to ambiguous loss. Regardless of age, when an adolescent is suddenly thrust into a changed family dynamic because of a TBI-P, the feeling of loss is present. Whether they mourn their old relationship with their parents or notice that their injured parent is not the same emotionally or mentally, there is a loss that must be acknowledged. Further, since the loss is not final, adolescents in the study were asked to navigate the process with less support than adolescents who experience a fatal parental injury, aligning with previous research (Boss, 1991; Estani-Dufour et al., 1992; Griffiths, 1997). Adolescents who experience a traumatic event like a TBI-P are processing the effects in a way similar to how someone would mourn a fatal loss. However, an injured parent is not viewed the same as a parent who passed away. Consequently, those working with adolescents affected by trauma need to be aware that a non-fatal loss can present itself in similar ways that a fatal injury might, and that extra support might be needed for the affected student. These supports include

focused emotional support, behavioral reinforcement, and academic grace as the adolescent processes their loss in a repetitive fashion.

### **Finding Two: Time Since the Injury Affects the Severity of Ambiguous Loss Feelings**

While ambiguous loss could be seen across all participants, one variable affects how strongly that loss is felt: time. This may be the most significant finding as prior studies had not explored time in relation to feelings of loss. One strength of this study was the wide range of ages of the participants, which ranged between 7 to 24 years old. Consequently, the wide range in age produced an interesting finding: ambiguous loss was more pronounced in older participants compared to younger ones. For Elaina and Paul, it had been approximately 15 years since the surgery had occurred. As a result, their experience exhibited stronger signs of ambiguous loss. This difference can be attributed to two different reasons. First, they had experienced their loss for a much longer time than other participants, allowing for a better view of how the TBI-P affected them over years of living with it. This sort of longitudinal experience allowed for greater reflection and for Elaina and Paul to engage in a useful comparison and contrast, giving insight into how exactly the TBI-P had affected them. From this vantage point, they were able to look at the totality of their experience, frame it within their life story, and discuss how it intersected with their emotions and perception of their family. This was a powerful benefit to including young adults in the study, in addition to young adolescents who were currently still living at home and processing the TBI-P event in real-time. The power of time in this instance was useful for the study and proved that ambiguous loss is a dynamic process. The further one gets away from the TBI-P event, the stronger the feelings of ambiguous loss could be.

Alternatively, younger participants had only lived with the TBI-P experience for less than three years at the time of the study. Consequently, the intensity of their ambiguous loss was much more subdued. I attribute this difference in perception to their age, emotional and psychological maturity, reliance on their parents, and the cognitive complexity that a traumatic injury produces. First, younger participants did not have the ability to truly process the TBI-P event as it related to their lives. Put differently, the focus of children in the study was different than the focus of young adults as it related to the TBI-P event. While young adults in the study had the benefit of time to reflect and logically work through their experiences, the adolescents were much more limited in their ability to conceptualize how something might affect them later in life. Secondly, as adolescents work to emotionally mature during their formative years, the young participants in the study were still in the growing phase of that process. As a result, they might not have had the emotional maturity to look at their situation in its totality. In turn, the adolescents in the study saw what was immediately in front of them, unable to look beyond the horizon to see what effect their experience might have on them as they get older. Finally, because adolescents are generally reliant on their parents, the feelings of ambiguous loss might have been weakened. Since adolescents in the study lived at home and actively participated in their family structure, they might have been more willing to overlook certain negative experiences in order to form a sense of normalcy. In this regard, even though their injured parent might have acted differently or tended to be emotionally unstable, adolescents chose to downplay the significance of their experience. This would allow them to retain their sense of family cohesion and work to protect how they viewed their parents. As it relates to time, it would be interesting to see if adolescents in this study experience higher feelings of ambiguous loss as the time since the TBI-P event grows wider.

**Finding Three: Ambiguous Loss Results in Tangible Outcomes for TBI-P Adolescents**

This study showed that adolescents who experienced a TBI-P event while living at home exhibited signs of living with an ambiguous loss. Further, this study proved that time is an important variable in determining how strongly someone experiences ambiguous loss, with more time since the injury producing higher feelings of loss. Another finding from this study found that tangible outcomes can occur after an ambiguous loss, ranging from immediate to long-lasting outcomes. Across all five participants, tangible outcomes were found, ranging from the positive to the negative. For Elaina, her decision to pursue teaching as a profession would be considered positive while Maggie losing quality time with her parents would be considered negative. Interestingly, while I assumed any tangible outcomes would be negative based on the existing literature on stress and loss, I was surprised to find that positive outcomes were possible, at least in the short-term. April offered an example of resilience, choosing to frame her experience with TBI-P as a positive development in her relationship with her father.

For Elaina, she experienced different tangible outcomes in her experience with her father's brain injury and surgery, including areas in the personal, professional, and emotional parts of her life. Personally, her experience with ambiguous loss left her with a sense of a lost childhood, which led to other outcomes, including her pronounced sense of having to grow up much too early in order to emotionally process the TBI-P and support her family. Consequently, one tangible outcome that remains to this day is to serve as a protector of her younger brother. Elaina's experience also resulted in other tangible outcomes, including her decision to pursue teaching. Responding to the loss she felt as a child of a TBI-P survivor, she developed an empathy for people that fed into her desire to teach and support children as they learned. As a

result, Elaina noted that her enhanced ability to empathize with others was a direct result of her experience with TBI-P.

Paul experienced much different tangible outcomes compared to his sister. Based on his experience with his father and how he had directed his rage and anger towards him, Paul was changed for the better. He noted during our interview that he would be intentional to treat his future children differently than how he was raised. The surgery and feelings of ambiguous loss had caused Paul to experience an emotional change, enough so that his future decisions were already being shaped by the experience. However, Paul also experienced negative tangible outcomes, stating that he too lost his childhood through his experience with TBI-P: “I maybe lost a childhood that probably could have gone better.” In addition to his feelings of loss, Paul also struggled to reconcile how poorly his father treated him over his formative adolescent years. In turn, he experienced a tangible outcome of anger directed at his father, emotional distance from his father, and emotional scarring from the constant negative attention placed on him by his father; whether the anger or emotional distance will decrease with time has yet to be seen.

For the younger participants in the study, the tangible outcomes were less pronounced. However, they were still present in some form. For Robert, the immediate tangible loss was losing his once-active father. Instead of playing outside with Robert as he used to, his father would spend much more time inside, causing Robert to lose a sense of closeness with his father because of the injury. Over time, this lack of engagement could lead to other tangible outcomes such as feelings of disassociation with his father. For his sister April, the tangible outcomes were positioned as positive outcomes, at least in the short term. April noted that her life had improved since the injury, mostly because her father was at home more. Beyond spending more time with her, April could not share any negative outcomes since the injury or related to her sense of loss.

However, for Maggie, the youngest sibling of Robert and April, she shared an opposite viewpoint. As the only sibling to share that her parents were arguing more since the injury, Maggie had already experienced a tangible outcome in experiencing the stress of her parents' relationship and was already processing their increasingly stressful relationship. Because of the injury, she had also lost quality time with her family, increasing her feelings of lost family closeness.

#### **Finding Four: Ambiguous Loss Can Affect Self-Perception**

The final finding of this study showed that ambiguous loss can affect the self-perception of adolescents. However, there are two variables that determine how much self-perception is affected: age at the time of participation in the study and time since the injury. Adults interviewed for this study reported much higher impacts to their self-perception based on their lived TBI-P experience. This can be attributed to the time since the injury, which would allow for greater reflection on their experience, time to mentally and emotionally mature, and more time to see any outcomes appear. For children in the study, they reported minimal impacts to their self-perception, most likely attributed to having less time to process the injury and to emotionally work through their experience. Young adolescents might not have the emotional or mental maturity needed to look at their situation in light of how they view themselves. Further, younger participants in this study had far less time living with the TBI-P, possibly shielding them from forming self-perceptions based on the injury. The younger the adolescent, the less it appeared that TBI-P affected their self-perception.

As a result of their experience with TBI-P and their feelings of loss, self-perception was affected in varying degrees with the adult participants. For Elaina, the unclear loss of her still-living father helped shape her self-perception, noting that she valued herself differently based on

her experience. Without her experience with ambiguous loss, she would not have felt the need to find her value through being seen as useful in relationships with others. Additionally, Elaina experienced a shift in confidence in the immediate aftermath of the surgery, noting she felt less confident. Eventually, this was followed by a gradual recovery, shaping her self-perception even further into her adult life. Her brother Paul, on the other hand, positioned his self-perception in relation to his poor treatment by his father. In his case, he chose to internalize his feelings of negative self-worth caused by his father's constant negative treatment and worked to distance himself from it. Consequently, Paul worked to find his self-perception outside of his experience with TBI-P, noting his experience did not define him but it also did not pass by without any consequence in his life. In Paul's case, the high levels of ambiguity caused him to see himself as neither a victim of his circumstances nor a victor of them.

For siblings Robert, April, and Maggie, their self-perception was slightly less altered than the older participants in the study. While Robert noted his growing emotional sensitivity to different situations, he was unwilling to go further in explaining how he viewed himself. For Robert, he felt that he had been unchanged by the TBI-P and that life had gone on normally. However, after presenting my findings to his mother to ensure their story was represented correctly, she agreed that he had definitely struggled with the injury and its aftermath. It is possible that his self-perception will be affected the further he gets from the date of the injury. For his sister April, her self-perception was not affected by the TBI-P event. While April shared that she was forced to alter how she asks questions in the family, most likely to avoid triggering her father, her self-perception was not based on her experience with her father's injury. The same is true for Maggie, who was not able to articulate whether her self-perception had been affected based on the TBI-P.

## **Implications**

The findings of this study have several implications for those working with and around TBI-P adolescents.

### **Implications in Education**

There are implications for educators and others in the school setting resulting from this study. First, educators must understand that adolescents are experiencing and navigating a loss that is similar to losing a loved one to death. While there are similarities in how adolescents mourn a fatal loss and a non-fatal traumatic injury, there is no closure for TBI-P adolescents as they must continually mourn a still-living parent. Shonkoff and Garner (2012) found that “exposure to...traumatic experiences can have a profound effect socially, emotionally, and physiologically” (para. 2). This type of experience requires flexibility by the teacher in their expectations of work by the student. Researchers have noted that exposure to traumatic experiences “can have an influence on neurological development” (Egan, Neely-Barnes, & Combs-Orme, 2011), “which can have a direct effect on learning” (Sanders, 2021, para. 11). Similar to how work might be excused or due dates flexed, teachers need to show flexibility in working with students as they process their grief. The inability to achieve closure, along with the burden of recalibrating their emotional and parental expectations, is a heavy burden on the still-developing adolescent mind, which calls for others in the school setting to offer support to the affected student. Consequently, the role of stress from the TBI-P event plays a role in how educators might respond. Kim and Diamond (2002) found that when children experience higher levels of stress hormones, their educational success was impaired. While too much stress can impair learning (Joëls et al., 2006), stress has even been found to occlude learning for some time after the stressful event (Joëls et al., 2006).

Just as one would not expect a child who lost a parent to death to simply move on, the same is true for TBI-P adolescents. Support from auxiliary school staff and counselors is imperative as school is normally where the adolescent spends the most time outside of the home. Aligned with the literature on trauma, the realignment of family responsibilities and roles places an enormous stress on the adolescent and treating TBI-P adolescents as if they experienced a fatal loss could create opportunities to help them deal with the changes in their lives. Stipp and Kilpatrick (2021) agree, noting:

With the brain in mind, trauma-informed education encourages teachers to be relational and to consider scattering therapeutic moments throughout the school day. It also emphasizes that teachers can empower students by being relationship coaches, attune to students' physiological needs of sleep, hydration, and nutrition, and correct misbehavior in a way that keeps the teacher/child relationship intact (Call et al., 2014; Wolpow et al., 2011).

As this study has shown, adolescents are often asked to take on more responsibilities after the injury has occurred, risking the loss of some part of their childhood. For educators in particular, TBI-P adolescents should be afforded the same emotional, behavioral, and academic supports as adolescents who lose a parent to death.

Further, the experience of TBI-P adolescents could be supported through the inclusion of trauma-informed practices in teacher education programs. According to the National Child Traumatic Stress Network (2014), "up to 40% of students have been exposed to adverse childhood experiences that compromise a student's healthy stress response" (p. 600). With such a high number of students who have been exposed to trauma, the addition of trauma-focused teacher training would add depth to teacher preparation programs and allow for teachers to better

serve adolescents. By supporting preservice teachers in this way, educators could have better supports to implement and to reduce the mental load that students carry. Ideally, this would take the form of a trauma toolkit and contain ideas, processes, and roadmaps for dealing with non-fatal, severe trauma. For educators, this might include developing a trauma-invested school setting where emotional supports are put into place to guide adolescents through their academics while also appreciating their continuous mourning. This type of preservice education for teachers could help to reduce the professional burnout associated with working with vulnerable student populations like trauma-affected students (Sullivan, Johnson, Owens, & Conway, 2014). Further, Pines (2002) found that teachers without trauma-focused coursework struggle with meeting the needs of trauma-affected students which works to reduce the satisfaction they get from their work. Not only will students be more supported, but teachers too.

### **Other Implications**

TBI-P adolescents need support well after the parental injury has occurred, as the time since the injury affects feelings of ambiguous loss. While it is vital to support adolescents in the immediate aftermath of the TBI-P, feelings of loss can persist for many years after the injury. Researchers have found that childhood trauma can affect people into their adulthood and even negatively affect their physical health (Anda et al., 2006; Dube et al., 2001). Whether this is continued psychological support from counselors or psychiatrists or having a trusted confidant to express their feelings, there needs to be more support built around TBI-P adolescents long after they've entered adulthood. This support needs to be longitudinal and focused on feelings of loss, including ways on how to process those feelings, which include opportunities to share or talk to others experiencing a similar situation:

Written emotional disclosure, or the Pennebaker paradigm (Pennebaker, 1997), has become a popular pedagogy across a number of disciplines. Studies have demonstrated positive benefit in writing about or revisiting painful experiences and emotions when the author is able to develop a new meaning or a new physiological response in relation to these events (Littrell, 2009)

While a fatal loss might allow some sense of closure, the recurring nature of an ambiguous loss requires a slightly different approach in how to deal with those feelings.

Further, TBI-P adolescents must be viewed holistically, as the TBI-P event affects far more than how the adolescent grows up. Their emotional and mental states can be stressed by the sudden and ever-changing environment, which can have lasting impacts on everything in their life, from relationships with their parents to tangible outcomes later in life. Researchers have discovered that trauma during childhood, especially exposure to multiple traumatic events, can lead to major health issues and even premature death (Brown et al., 2009; Clemens et al., 2018). Schools already offer multiple support systems for trauma-affected students, including counseling, behavior plans, and case management services. However, offering a trauma-informed approach might include a holistic approach to include personal supports that allow adolescents to express their emotions through continued conversation and therapy beyond impersonal counselor sessions. This approach would also include professional supports to teach adolescents how to process and navigate their experience through learning opportunities and debriefing sessions. Finally, the inclusion of educational supports should take into account the stress they are under, and include reduced coursework and flexible due dates for work. Most importantly, educators must work to ground adolescents in their experience by allowing space to

discuss and explore the feelings of the adolescent's experience. This type of work falls to educators in the school setting according to Crosby (2015):

Schools have a significant impact on youth well-being, being the most common institutional entry point to mental health services (Farmer, Burns, Phillips, Angold, & Costello, 2003; Ko et al., 2008). Implementing trauma-informed practices in educational settings can assist in creating environments where traumatized students can be successful (Cole et al., 2005; Wolpow et al., 2009).

By viewing students through a dual lens of academics and personal struggle, educators can move to a holistic view of students, allowing greater supports to be implemented and to enhance the healing of the adolescent

### **Recommendations for Future Research**

As the field of ambiguous loss is in its infancy with minimal research focused on the concept, there are a multitude of future research opportunities related to TBI-P and ambiguous loss. While this research study was not longitudinal in nature, one area of future research could focus on how ambiguous loss affects adolescents over the long term. In this instance, what are the effects decades later? Another area of future research could focus on how positive coping could affect the severity of ambiguous loss later in life. When trauma is experienced in childhood, it is expected that the trauma will affect adolescents for many years. Does mindset play a role in the severity of ambiguous loss? Further, researchers could explore if ambiguous loss ever peaks, reduces, or flattens out based on the time since the injury. Does the adage hold true that time heals all things, specifically relating to trauma? This research focused exclusively on adolescents and their perception of their experience with ambiguous loss and TBI-P as told in their own words. Future research could greatly expand on this experience by including a mixed

methods approach, integrating self-reporting instruments to measure variables such as participant depression or PTSD. Another addition to future qualitative research studies on ambiguous loss could be the use of a critical friend in challenging findings from the study. Similar to member checks, this approach would help to ensure bias is monitored and that the researcher is not injecting their personal experience into the results or forcing outcomes to match the expectations of findings.

### **Summary**

This study was one of the first to focus specifically on TBIs/TBI-Ps and ambiguous loss, positioning this research to make a contribution to the larger field of traumatic brain injuries and adolescent response-to-trauma research. The findings of this study indicate that ambiguous loss does affect adolescents in different ways, a new finding that adds to existing knowledge to the still-developing concept of ambiguous loss. From losing a sense of innocence in their childhood to struggling to emotionally process their experiences, TBI-P adolescents were impacted by their experience with ambiguous loss. Consequently, another finding of this study relates to the time since the injury and the severity of ambiguous loss feelings. Ambiguous loss was more pronounced in older participants compared to younger ones, indicating that feelings of loss might intensify over the long-term. Simultaneously, TBI-P adolescents also showed resilience in light of their feelings of ambiguous loss, making it possible that mindset can alter their experience and lessen its impacts over time. While ambiguous loss resides in the conceptual, this study also found that it can result in tangible outcomes later in life. Whether these outcomes happen immediately or occur many years later, the stress experienced during the TBI-P event and aftermath can result in outcomes tied directly to that experience. Finally, self-perception can be affected by ambiguous loss. In relation to time, there was a greater impact on self-perception in

older participants than younger participants. Consequently, future research is needed to add more depth to the concept of ambiguous loss.

### **Conclusion**

This dissertation began with my story and how I dealt with growing up with a brain-injured father. While I experienced a volatile childhood at times and struggled to comprehend my feelings of loss, I would not recognize what I had gone through until my time in my doctoral studies. Through the exploration of existing knowledge in stress, PTSD, family system effects, and ambiguous loss, it became clear that experiencing the non-fatal loss of a family member created many concerns for adolescents. Had our family known about this concept of ambiguous loss and understood how we needed to approach it, perhaps our experience might have been different. While a TBI-P is a unique experience to every adolescent, this study has shown that there are some similarities in how they experience stress, feelings of loss, and a sense of continuous mourning. This study adds to the knowledge base by being one of the first to connect the concept of ambiguous loss to TBI-P. Future research will offer exciting opportunities to further explore this concept and to offer new and innovative ways of working with TBI-P adolescents.

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**TABLES**

**Table 2.1**

*Participant Demographic Details*

Participant	Sex	Age	Race
Elaina	Female	23	Caucasian
Paul	Male	21	Caucasian
Robert	Male	15	Caucasian
April	Female	14	Caucasian
Maggie	Female	7	Caucasian

**Table 2.2**

*Interview Details by Participant*

Participant	Length of Interview One	Length of Interview Two
Elaina	62:00	15:01
Paul	51:28	22:32
Robert	32:16	N/A
April	24:46	N/A
Maggie	10:01	N/A

## APPENDIX A- INTERVIEW QUESTIONS

### Injury Background

1. How old were you when your parent experienced their TBI?
2. How did your parent receive a TBI? What happened?
3. Was the TBI classified as moderate or severe?
  1. If unsure, probing questions regarding the nature of the injury can be inserted here, such if the parent was hospitalized and unable to work (and for how long for each)
4. What grade/how old when the injury occurred?
5. What was your immediate reaction when you first heard the news/experienced the event?
  1. What do you remember about feeling any sort of emotion at that point in time?

### Evaluative Questions

1. What was your family life was like before the head injury?
2. What about your academic life? What was that like before the injury?
3. Describe your personal life before the injury.
  1. How were your relationships with your family?
  2. How was your relationship with others?
  3. How did you view yourself before the injury? “Before the injury, I was \_\_\_\_.
  4. Can you recall any noticeable changes in your behavior or emotions after the TBI?
    1. Were these behaviors or emotions present before the TBI?
4. In the immediate (6-12 months) aftermath of the injury, can you describe your experience?

1. Did you notice any *mental or emotional changes* in your parent? If so, could you describe the changes?
2. Did you notice any *physical changes* in your parent? If so, could you describe the changes?
3. Did your family experience any *relational changes*? If so, could you describe the changes?
5. How do you think the TBI personally affected you?
6. As an adult, did the TBI-P affect your:
  1. Professional life? How?
  2. Family life since the injury? How?
  3. Personal life? How?
  4. Other?
1. From your experience with TBI-P, has your stress level been impacted since the accident?
  1. If more stressed: What has caused this additional stress?
    1. Do you think the accident played any role in your additional stress over the last few years? Why or why not?
  2. If less stressed: Why do you think the accident has not affected your stress?
    1. How did (or do) you cope to ensure that stress doesn't affect you?
  3. If unsure: How do you deal with things in your life that are not ideal or expected?
1. When the accident occurred, can you describe your emotions during this time?
  1. What did you feel?
  2. If you felt any emotions, how were you able to express them?

1. Did you have any opportunities to discuss your feelings with your family?

Why or why not?

1. Since the accident, do you handle stress differently?

1. If so, can you describe how you handle stress now compared to before the accident? Or vice-versa?

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1. After the TBI-P, can you describe your performance in middle and/or high school?

1. What did you notice about your school performance (grades) as you moved closer to high school graduation?

2. Looking back, if there were any changes, where do you think those changes started?

1. Looking back since the injury, how would you describe your life now compared to then?

1. Since the injury, how do you feel that your life has improved? Gotten worse?

1. In your opinion, how well do you think you've handled the TBI-P?

1. Do you believe that you went through a difficult time in your TBI-P experience?

### **Closing**

1. If you had to offer advice to adolescents going through a TBI-P, what would you say to them?

1. Is there anything that you would change about your experience?

1. Is there anything else you would like to add before we end the interview?

## APPENDIX B: INTERVIEW TRANSCRIPTS

### Elaina First Interview

WL: How old were you when your parent experienced their brain injury?

Elaina: Actually, I have dates. So, I'm going to give you dates so we can keep...because it all blurs. So, my dad had his initial injury on October 28, 1991. That left him with epilepsy, that progressively got worse over the years. So, when I was in fourth grade, that was August 2007, and so I would be nine? Nine? 1998. Nine. He had a left temporal lobectomy, and that was when we saw things change. So, it would be, I was nine, fourth grade is kind of when things...I was negative eight years when he had his initial injury.

WL: (laughs) Yeah, wow. That's similar to my story. Then, do you know what happened, like how did he receive the brain injury?

Elaina: Yes, so, okay. He was an airline mechanic, which he still is. He was working night shift. He was up on a ladder doing something that I do not know. When he was coming back down, his leg got wrapped around a wire of some sort and he fell, I don't know how many feet. But it was pretty...it was headfirst. Cracked his brain open. Went to the hospital. Uh, and...[slight pause, "oh gosh" whispered]...I am 90% sure he was in a coma. I mean, you have to be with that.

WL: Mmhm hmmm.

Elaina: And that is actually, side note, where he met my mom because my mom was a vocational therapist and he had his coworker write a letter that it would be good for his social and mental health if he took her on a date.

WL: No way! Awww. That's so sweet, oh my gosh. Wow. So I am going to guess that was a severe traumatic brain injury?

Elaina: Yes.

WL: Versus like a moderate or...okay. That's fine there. For the study, I am kind of excluding the lower end of the spectrum, so like moderate to severe...because like, concussions and stuff like that, they can have some effects but nothing like you and I have gone through for sure. Okay, so you were in fourth grade...that's there. Do you know when you first learned about the injury? Do you remember a memory?

Elaina: It's one of those things where because he, I think...one thing is he had it so long before...even before my mom knew him, technically, it's just the way things were. And, like, I thought everybody's dad has seizures, like, they do that little weird dance, ya know, and say those funky words. That's just how I grew up. My mom did a wonderful job of explaining it to us but it's one of those things where it's not she sat us down and was like "your dad has an issue." It's just kind of the way we lived because it happened before we were born. I know it

progressively got worse, and so that's when we had more conversations like, "oh, this isn't normal and it's especially not normal for him to have these many seizures."

WL: Got ya.

Elaina: And they were not grand mal, they were...the other one. I forgot the word for it. Anyway, he had not had any grand mal seizures at the time, just the frequency was going up.

WL: Got ya. Got ya. Got ya. And, then, whenever you finally realized that, did you...tell me, like did you have an emotional response to that? Were you sad, worried, anxious, or was it just...

Elaina: Well, I...do this great thing that many people do, I internalize a lot. Very much so. And so, I was smooth sailing until fourth grade. I mean, I am talking straight A's, good two shoes, you know, life was poppin'. And then in August, he had the surgery and I acted like everything was ok, but I wasn't turning in stuff. I wasn't turning in homework. I wasn't necessarily acting out but I wasn't engaging in class. And I just couldn't...I was like a mess. I would do the homework, I just wouldn't turn it in.

WL: Uh huh.

Elaina: And so, my mom, being an all-star mom, she was like, "ok, what can we do?" And so she met, had more accountability for me for both doing it and turning it in. Like, I had a system with the specific folder and getting that in. But, socially, I just like...fourth grade, I didn't really make any friends either, as well. And, 'cause my mom and I debriefed before this, she mentioned that...and I didn't really connect the two. I was like that until she sat down with my brother and I and said, "you know your dad is going to be ok, right? Like, he's not going to be the same that he was before but he's going to be ok."

WL: Yeah.

Elaina: And that's kind of when I got better. You know? When you see...when you are in that hospital for a couple of weeks and you're going in and out...your dad had a brain surgery. You don't know what that is. You think, is he on the brink of death? Like, what's going on here? So, when she kind of relieved, that kind of helped everything else kind of level out. Become normal.

WL: Yeah. Our story is so similar, it's crazy!

Elaina: Really?

WL: Yeah. It was the same thing. I was acting out. Not turning in work. I didn't know why. I just knew something didn't feel right. And then, years later, I'm like...oh! Ok. Now I understand it.

Elaina: Yeah! And it's so funny how those things stick with you because I specifically remember I was put at basically the bad people's table with kids that like...they...I think they were going through the same thing I was, you know, but I was so intimidated because they were like...I just imagined they were mean kids. Like, they were mean to people. While I would kind of act out, I

don't ever think I was mean or malicious about it, but like things I'd say, you know...just kind of the whole...and I was thinking, oh my gosh, this is my group now. And I didn't want that, you know? These were not the friends I had before and we went to Business City. I don't know if you know what that is. Business City, was really, a great idea. If they still do it. But it's a place in town where they take you for a day and you have a role in their small society and you're given a paycheck so you do your work for eight hours and then you go and get to buy from other vendors which your classmates are working. So, it's kind of fun. But because I was irresponsible, they put me, like, in the back...like literally counting erasers and I was thinking...this is my life! I'm just gonna...this is gonna my life for 40 hours a week when I graduate. This is it.

WL: This is it!

Elaina: You know? And, I remember the emotion. Even looking back, I was like, I'm not gonna say necessarily I was traumatized by it...but it definitely shaped me in a way, where I was like, oh that was not a good year. It's just, I just...I didn't have the, have the mental or emotional capacity to make good decisions. I think that's what it was.

WL: Yeah.

Elaina: And my mom did a great job. She tried to take us to counseling...I didn't even get it for some reason. Because, he (the counselor) would give me, literally homework! He would say, "ok, these are the things you are going to do this week." What?! Who gives you homework when you don't even do the homework from school? Like...I do now have a therapist so I have helped that relationship with people who do that kind of thing but definitely, a rocky year.

WL: So this one doesn't really apply, which is more like what was your family life like before the head injury. So if your dad had it before you were born and before he met your mom, so...

Elaina: Well, there was still a vast contrast between before and after surgery. Because, I'll be honest, I think the surgery had a much more impact on my life than the brain injury, since I didn't know that contrast. But, my dad originally was, and he's getting there now, a very just happy go lucky, supportive guy. Like, excited be with us. In fact, I was thinking about this, I still love horses. And we couldn't afford to do much, so he would actually take me to local horse shoes and like, we'd watch horses and he would...he would ask if I could pet the horses and stuff. Like, outgoing guy. We get the surgery, and then you know, you kind of have to see your dad relearn stuff. So, I remember, like, teaching him what the word remote meant and things like that. And then he was on Keppra (Levetiracetam) and got the Keppra rage. And, was just so irritable and angry. And it would just be the oddest things that would set him off. Like, I remember we were at Disney World and my brother asked for a snack, that he had saved from earlier that we had brought. And he (the dad) just lost it. He just went into this whole rage and stormed off, and we didn't see him for the rest of the day. And it was like, that is not the guy I know.

WL: Yeah.

Elaina: And that lasted about three or four years...he's been many a different people. He'd drive so aggressively and now...how many years later, 12, 13 years later...This man always goes five miles underneath the speed limit. So nice and easy going and I don't think he has literally gotten angry at anything in the past two years. And I so thankful for the transformation, but what's funny is, he doesn't remember any of it. So like, anytime he says something that kind of, that's like, what I would take as snarky because of how he used to say it, I get all...you don't remember! It used to be used against me, ya know? It's like, how do you rebuild that? So yes, he went from very happy, easy go lucky to really angry. I think he was also frustrated about his situation as well, understandably. And it was all his mixes in medication...I think that's kind of the formula that caused the great divide.

WL: Yeah. Absolutely. Yeah, because that all does it. Happy...raging.

Elaina: So, did you have any siblings?

WL: Yeah, older sister, she's six years older.

Elaina: Yeah, it's just interesting...I can see if my brother wants to do it. But, my brother is younger, and it's so funny because my dad really butted heads against my brother. Like me, I was pretty okay, I could kind of get through...the thing was I was old enough to make better decisions, what to say, what to do versus my brother who was just like headstrong (who was like, no...unintelligible whispering). And, for a while in high school and middle school, but Paul would go through this cycle where he would start to try, he would do something, and I'd be like "it's not gonna work...I've done it too, sorry, so I can stop trying." I just kind of had a very distant relationship with my dad. My brother would keep trying to like, re-...then it would blow up in his face, and he'd be like, "I don't understand." Like, how did you not see that coming? Like, are you blind? We all see it coming. You get mad, he gets mad. It just, spirals out. And so, being the older one, I felt like I didn't only have to manage my situation but manage my brother's situation and try to look out for him...it's just that teenage boy brain.

WL: It's different though, different ages experience it differently. That would be very interesting to see. Ok, well that's helpful, thank you for that! So, I know you said in fourth grade, kind of your academics might have just went off a cliff a little bit there...

Elaina: Yeah.

WL: Did they eventually, did they come back around?

Elaina: Yeah, 5th grade, I got back up, started doing it again. I think one thing that helped was, so...I had a speech impediment and I was on track for the gifted program. But fourth grade, the school was kind of, I guess, trying to figure out what to do. And, they basically said, "listen, we can only do one or the other." And, so, which, I understand, they put me on a speech therapy program which took me away from a good bit of the friends I did have that would have stayed in the program. Got back in the program in the 5th grade. And so, I think there was a rude sense of, ok, maybe I am special. I can do this, you know. And, I don't have to be kind of the flunk out fourth grade. I can kind of be myself. So I think that kind of helped cause, I mean, it was literally

called gifted and talented which was such a thing. So you feel more special, I think...I was also back with people I actually knew so that helped.

WL: With your friends, yeah. And then, after that, moving on up through middle school and high school, I think we'll circle back around to this...but were there any residual effects from your experience growing up with your dad with the head injury, you think?

Elaina: That is a good question...um, in middle school, things started evening out as much as you can. My dad hadn't had as many explosive kind of things. I'm trying to think. There was still...oh man. I did still internalize a lot, and so I think there was. And I think it came out more in our relationship more than it did in academics.

WL: Ok.

Elaina: And I think one thing that did help in high school, my dad started a job where he would travel, so he'd be gone for three or four weeks and then home for three or four weeks. And so, it's kinda, I hate to say it, it was kind of nice when he was gone, and that kind of, I think, gave me space to kind of work on stuff. In high school though, I saw more...you just kind of pick up more on stuff, and I realized my parents' marriage was not...you know, happy go-lucky, you know. And that is when I think...cause I was goody two shoes again in high school, but it was more of I guess with my...relationships with my friends. Because, I started seeing what their dads were like more, because I would actually go over to their houses and see, oh...not all dads are like this. That's weird. And I think I got more jealous than anything.

WL: Uh huh, yeah. For sure.

Elaina: Like, what the heck? Why do you get a normal dad?

WL: Yeah, I know...my dad doesn't act this way.

Elaina: I know.

WL: Yeah, so is that relational thing you are talking about, like, versus the school...you saw more things in relationships with friends, like that jealousy of like, why's your dad normal? Why does my dad have an injury?

Elaina: Yeah. And I think it was...part of it was, we never really invited people over because you know how my dad was gonna act. And when you see all of my other friends say, "oh yeah, we hung out with so and so's family last night, we hung out with so and so's family last night," like no...we did not. You know? Like, we don't really invite people over. We had a really small house, we still have a really small house, and with the way my dad was, it just...and even when he was gone, I made a point, like, if I invite someone over, who's there? And so, we just didn't invite people over and there was like a, man...I feel out of the realm of what's normal. Like, we never had family friends growing up. You know? Why can't we have family friends?

WL: Right.

Elaina: And, now that my dad's more normal, now we're getting family friends or we're inviting people over. And I'm like, oh my gosh. I feel normal now! I've established the full realm of confidence of coming back to it (laughing).

WL: Just took a little bit longer than other people!

Elaina: Yeah!

WL: Well, ok, when was your dad's injury/surgery you said?

Elaina: 2008.

WL: 2008, okay. Put that here so I don't forget that. So, how would you describe your relationship with your family, kind of before that? Like, if you had to choose a few words.

Elaina: Consistent. Very supportive. And, more like a unit.

WL: Kind of like you guys were together, going at life together, full support.

Elaina: Yup.

WL: And then, this is all kind of before the surgery...what about your relationship with others, like friends?

Elaina: Very healthy, I still was a little bit of an odd man out, definitely a quirky kid. Because, at the elementary school I went to, almost every single year I would change classes. I didn't know anybody in the class. Which my mom was like, "I hated for you," but at the same time, she kept saying, "yeah, but you're making more friends than anyone else in the school!" At the same time, like, "this sucks for you!" (Laughing). You know? But she's like, "I don't wanna be one those parents...like, I understand to work in a school, so it is what it is kind of thing. But I think I was very confident socially, academically, and emotionally. Like, yep, this is who I am, this is, you know...I definitely had a, like a reverence for authority, like if the teacher said it, it was in gold. You don't mess with it. And maybe that's why I am a teacher now, (laughing), I don't know!

WL: Teaching is so much fun!

Elaina: I know!

WL: Ok, so we're still before here...so, finish this sentence for me. It's like, how you viewed yourself before the injury. So before the injury, I was \_\_\_\_\_.

Elaina: Hmm...oh man, I am slow with words. Ok, I gotta talk through this one. Because my first thought was...kind of like, untouched. I don't think I was really grounded by reality. I really thought I could really shoot for the stars. So like, I had lofty dreams. I didn't know what those

were, honestly. I wanted to be a disco dancer and secretary, so that was it. And, I didn't know what conflict looked like. I didn't know what any of that looked like. So, I guess, I wanna kind of say aloof.

WL: Aloof? Ok. Yeah, that's work. So, how about immediately after that surgery, did you notice anything different about your behavior or emotions, like, surgery happened and you were acting out a little bit at that point or was it a little delayed? [author's note: the participant already identified that she began acting out earlier in the interview]

Elaina: Oh, it was pretty much at that point. Because, I'm really, with the timing of that happening in August, I was going back to school. I was very, a lot more, reserved and distant from people. Like, obviously, I'm very chatty, was before. But, I put a lot of distance between me and my friends. Things like that. I usually would be the first one to raise my hand with the answer...did not engage in conversation with the class at all.

WL: That's interesting, yeah...And so before that, before the surgery though, you would have been one to be like, "yep...right here."

Elaina: Oh yeah! I was the annoying kid, yep. The one that would (pretends to raise hand).

WL: How about that...as much as you can remember that year after the surgery. Can you describe that experience, like what you went through. Because I know you were, kind of, a little more reserved, a little more distant with people. Do you remember anything about that? That first year after, where you mindfully like, something is wrong?

Elaina: Yeah, I kind of remember being on edge all the time. Like, oh my gosh, what is going to happen now? Anxious. Anxious. You know, when you're young, you don't really know what that means. I remember the constant feeling of like, I had a frog stuck in my throat. And I just wanted to cry at any minute. And yeah, 'cause I can't pinpoint even a single really good memory from that time or year.

WL: Yeah. We already covered this one, you did notice some mental or emotional changes in your dad after the surgery?

Elaina: Yeah.

WL: Ok.

Elaina: And if you want to be more specific, it was kind of...name recognition. Processing, And, memory, both long and short term memory.

WL: Yeah. Then you already mentioned, did the rage or anger start around that time as well?

Elaina: You know, my perception of it...and my mom may have a different one, I feel like it was delayed. Because, I know he was frustrated but I feel like the true, what my mom call the bad

years, those were a little late because I think my dad was still trying to process everything that had happened, you know, on his side of things. I don't think he was on Keppra yet.

WL: Got ya. And what about his work situation? Do you think...was he pretty upset that he couldn't work or couldn't do things he used to do?

Elaina: Oh yes, definitely couldn't do the things he used to do. So both in a vocational, but also just like a functional perspective. I think a little bit of work...my dad does this thing where he always jokes, he's like, if you're ever gonna get injured, you need to get injured at work so that they pay for it. So like, we're okay...the union gotten him, so he was okay financially for us to go through that season. But I think he was definitely ready to get back to work. That's where he feels useful.

WL: Yeah.

Elaina: Oh, actually, an update since the last time we talked. My dad...I don't think I told you this. In February, my dad was in Australia, he was working. Was flying back over, in the flight between Los Angeles and here, he had six grand mal seizures on the plane. And thankfully, literally by the grace of God, there was an ex-EMT that was in the row like, next to him and saw that he was having his usual seizures...swinging the arm, the kind of muffled speech. And then, went in grand mal seizures which he had never had before, which was super strange. And he checked his vitals after every seizure, his oxygen level would decrease to a dangerous amount, lower and lower. So, they had to land the plane in Denver, Colorado. We flew out there, he was in a medically induced coma because they said something was wrong with his lungs, his breathing wasn't right. Which was odd, because he's a very healthy man. Like, he bikes 4 or 5 miles a day. Like, very healthy man to be doing what he is doing. And so, thankfully by the time I got there, like 2 days after the incident, he was out of the coma but still like...my mom's name was Tammy and I was Kimberly, and you know...just trying to come to terms with it. Now he's...his processing is still a bit slower but he's making a full recovery which is amazing. But anyways, that brought up some stress that workers comp put on before so thank goodness we did not have private investigators. But you know how companies like that can be, they're losing money. And, so it was like, they would fight my parents on everything and thankfully, we had an amazing workers comp lawyer at the time, who, she really fought for my dad. Without her, we probably would not be able...we would still be paying medical bills.

WL: Right.

Elaina: Yeah, so he was also like, if you have [get hurt, get hurt at work]...like, at what cost. Because, the amount of times they had to drive to a different city to have these conversations and my mom had to take off work and...it's so hard.

WL: That's scary. Yeah. I mean, it's hard on your dad. It's hard on your mom as the caregiver. It's hard on you guys as the kids and the worriers and also the caregivers.

Elaina: So, I don't know how it pertains to your research...Yeah, it definitely was. It's one of those things where, his seizures were like, I don't know...nothing big [referring to seizures he

had prior the grand mal seizures]. But I cannot mentally wrap around what that looked like, my own dad had a grand mal seizure. Because...oh my gosh. It's one of those things where, the entire time I was trying to think through this, trying to get...different people are telling us stories about what happened on the plane, and it's like I can't...I can totally, clear as day, see him doing his normal thing. But, because of the lobectomy that was on his left side, the seizures he was having were mainly on the right. Like, they were all...anything about the grand mal seizures was on the right. So much, that the EMT thought he was having a stroke instead. Yeah. Yeah.

WL: Yeah, and that's just another story of watching your dad...watching your once healthy dad go through that stuff, it like rips your heart out.

Elaina: Yeah. Well, you just think it's over. Like you know, we've done it. We've had the surgery, we've gotten to a good homeostasis of medication and now he's on the up and up...now he's an enjoyable person to be around. And now, this happens? I finally got a good place, a good place? And this happens? And it's one of those things, because I mentioned I internalized it. I had such a rough time. Well, I think anyone would kind of come away like, oh my gosh, what's happening. But, I started seeing a therapist again because I just had the frog in my throat. Like, consistently. While I would be teaching, every single time, I was like "I just need to get to my planning period so I can cry." I just felt so overwhelmed and I realized I had all this stuff I had not dealt with from my childhood that it really triggered. Right? This idea that my dad is in the hospital because of all this, seeing my mom had to be the caretaker again. You don't know what this is going to look like, you know? It's like, it rewoke all this stuff from my childhood.

WL: Yeah. So, how was your dad like before the surgery? Like, physically...was he active?

Elaina: Uh huh. Yeah, I mean, he was a mechanic, so he had to be physically...relatively fit. I don't think he took his health as seriously as he does now. Now he, honestly, only eats fish and salads and works out religiously. But he was a relatively healthy person. He really enjoyed walking and biking. So, definitely, he couldn't go to the Olympics anytime soon but he...he had a, he just enjoyed the outdoors, being healthy that way. So no restrictions that way.

WL: Ok. And then, we already talked about this...the relational change between you guys, like your family, before the surgery and after the surgery.

Elaina: It felt like before, we were a unit. Then it became, like, it was three versus one. To be honest. Because, it wasn't like...like I mentioned, it was me looking out for myself but also my mom and my brother right? Cause, he'd get mad at me less. And so, which helped create even more of a divide. But it definitely felt three versus one. Like, now, there's a stranger in the relationship. Like, he got swapped out for somebody else.

WL: Which is tough, I know it. Ok, so let's go on from this then. Do you think that your dad's surgery and brain injury, did that affect you in your professional life? Like your choice to teach or do anything like that?

Elaina: 100%, actually. My mom worked in traumatic brain injury research and I have always been so passionate about the brain and psychology, because I eat that stuff up. Because, my mom

and I joke, we live with a very interesting case study. So, like, we see it right there! I see a perfect example of how different parts of the brain, if you remove them, how that works. And so, that made me really passionate about people, but also, especially I think, when you are the older sibling in the situation, I'm trying to look out for my younger brother...I love to help people. Like, just guide them through situations, talk with them, see growth. Which my mom did as well, she said she literally went to college to help people. That's the only thing she knew she wanted to do. And, being an art teacher specifically, art is how I work through all of that. Which. I mean, I'm not going to put this on my therapist...I wish I had connected more with an art therapist at the time. I feel like that would have definitely helped me because that's much more my language.

WL: Right.

Elaina: Because I...it was kind of like kid who have a blankie. My thing was my sketchbook, I always had it with me and I would always be drawing. So that was my thing, that was my way of...cathartic release, of kind of, going back to the idea of confidence...it was a huge part of my identity. The friends I had, I had because I made in art class. Middle school, I think, was a much more enjoyable time because I had an awesome art teacher who really poured into me. So, that definitely led me to the steps to where I am today. I love the brain. I'm interested. I like teaching. But I love helping kids realize would a good tool art can be.

WL: Yeah. Teaching is so fun, I love it! How about now? So, as an adult, the injury and surgery...I know it affected your family life growing up. What about now that you guys are all older?

Elaina: Oh man, ok. Specifically in college, I went through the great reckoning of trying to work through a lot of stuff that happened. So like, I know that kind of happened again, but, it was actually in college. I was in campus ministry and I was being disciplined by kind of the leader of it. And, we were talking about how I view God as a father. I feel like people go down two paths: there's the whole, I don't trust him because I don't trust my dad. That was not necessarily it. I fell more into my faith, which is why I think I was okay during high school as much as I was. Because, I was like, you know what? I may have a default, you know, worldly dad but I got one up in heaven who's a-ok. But then I realized, the relationship I had with my dad was actually affecting my [unintelligible] relationship. Any time I called my dad, I would always start with good things he would have been proud of first so he wouldn't get upset. And then I could kind of talk about other stuff. And I realized, in my prayer life, I was like "look at all this stuff I'm doing." And then I can actually tell you about what's going on. To kind of like, prime him or something. Make him not upset with me.

WL: Right.

Elaina: And so, seeing that relationship...the guy I was discipling, pointed it out, like, "I know you said you separated these two but you treat them very similar." And I was like, oh my gosh! Oh my gosh, I do. And then, oh my gosh, what is my relationship with my dad and kind of going through the cycle. And I think, leaving the house I grew up in, being at college and away from that, away my dad actually helped me look at things from a different perspective and process with my own space and time. Because, I could go a couple of weeks without talking to my dad to

really work through it, so when I did talk to my dad, I had things that I wanted to talk to him about.

WL: Right.

Elaina: And, you know, kind of talking about that last thing. Because he can't remember any of it, he doesn't remember how he used to be. He doesn't remember the effect that it took...he doesn't actually remember a lot of our childhood. It's hard to have conversations about forgiveness with someone who doesn't remember what they did.

WL: Right. And then it goes on to you, you're like...you're the one who has to do the, "I forgive you...but you don't even know what you did...I didn't do anything."

Elaina: I know! I'm doing all the footwork here!

WL: I know. What about your personal life? I know you said you were engaged, did the injury or surgery affect you in that...like about who you selected as your partner?

Elaina: Oh my gosh, so, okay. Here's the thing: I...you know how everyone says, "you will marry your father, you will marry your mother." Whatever. Not me. In fact, if anything, this has primed me to not to do that. And while my fiancée does not have a brain injury, he's...oh my gosh, he's my father! I realized this over the past year, and I really had like uh, "oh my gosh, I'm gonna need a day to take a breather and re..." because I always thought they were so different. But, while my dad is very much more hands on and fiancée is more like, just give me the numbers and I'll work with it, like, it's these little quirks that I can appreciate. So, my dad, while it's a mess, he does have some very good qualities which are, I realize now, the very same good qualities I see in my fiancée. Like, my dad has always tried 110% to support us and make sure that, financially and everything, we are cared for. My fiancée is the same way. He will do anything he needs to, to protect his family to make sure they are going to be okay. Things like that. The things that I do enjoy about my dad, I realize, is probably why...I chose my fiancée.

WL: Yeah.

Elaina: Which is, it's a funny thing, like these small things. Like they both clean up the same way. My fiancée picked up a fork one time and said, are you done with this? And I completely lost it on him because my dad would always...he would be pinicky about things, like, "are you finished with this?" So when my fiancée would do this, I would be like...ahhhh! That is a loaded phrase for me because it never just went, "are you finished with this?" It was, "how dare you leave this out" and I'm gonna, kind of, lose it on you. So I am processing it. I...And the other thing is, I'm actually building better relationships with people who knew my dad before his injury and surgery from California. Because now as an adult, you know, it's easier to have these conversations. He's had a close couple of friends who knew him for the past thirty years and...I...I don't know. It's kind of like going into an investigative documentary about your own life because I'm now asking them questions I didn't know how to ask in fourth grade. So, what part of this was my dad before the surgery, and what part of this was my dad before the injury? Or you know, things like that.

WL: Right. It's kind of the same thing you mentioned, your family earlier...as a kid, you don't know what's all going on in the family. Or all the drama. Or all the stuff. You find out about stuff.

Elaina: Well, and... one thing is, it's like okay...so I went through high school fully confident in my parents were going to get divorced as soon as my brother graduated high school. Like, it was just going to happen, you know? And it didn't. I'm like okay, maybe they're trying? I don't know. We'll see. And, then, things got better. He was just more cognizant about the things he was saying and the things he was doing. He actually started doing things like sending mom flowers and really trying. And so, my mom's kind of been now, going through a process of, okay, like...what do I do here? And, clued me into a lot of that. She mentioned she probably shouldn't have told me everything that was going on, but I appreciated it. And I'm glad she did. But now, my new marriage is very complicated. Because I am like, how the heck do you guarantee your marriage is going to work? Like, it's just, of my gosh!

WL: Yes, so many moving parts.

Elaina: Yep, so many moving parts. And then my fiancée...his mom has had three marriages and so, we both joke like, we don't really know what a good marriage is supposed to look like. But at least I had family members who had very good marriages and relationships and were more than willing to, like, bring me into their homes and show me what that's supposed to look like. My fiancée didn't have that growing up. And so, trying to build as an adult where I think so many other people are so blessed to be conditioned to know what a healthy marriage is supposed to look like, I don't! I'm reading books about it because like, I don't know! You know? It's not even like a normal marriage issue, it's my dad had a traumatic brain injury and can no longer communicate his needs or understand and process what we need.

WL: Right. I mean, it's already hard enough to be married but then you add on that it's just like, unbelievable pressure, especially for the caregiver.

Elaina: Yeah. So, I know that was a whole loaded thing!

WL: No, I love it! Thank you. So, how do you think your stress level has been impacted since everything happened?

Elaina: After the surgery?

WL: Yeah.

Elaina: \*pauses\* Yes. And I think it also, like, unlocked this...I think I empathize a lot more with people than I did before because I didn't really understand. But I have a lot more empathy. I...professionally, I give my heart out to my students. Like, they don't know this, but I would put my life on the line for every single one of them. I would do anything because I...while we may not all have the same story, I know what that turmoil looks like. And, my poor kids...I know they're going through stuff even way more complicated. So, definitely empathy, understanding

kind of just the reality of the world, I think came a little too early, I think, is basically what it is. Like when I look at my kids, I think “you are sixteen and should not have to deal with that.” I was in fourth grade, and totally should not have went through it. If we could have postponed it, that would have been great.

WL: I know, it’s terrible. But it does make you more aware, because you are like...this kid is acting out and I don’t know, but it has to be something and so...I remember acting out, so let’s figure out what it is.

Elaina: Yeah, so when you’re not turning stuff in, there’s probably something else going on here.

WL: Right, yeah, stuff we don’t know about.

Elaina: Yeah.

WL: So I know you were stressed out years ago when everything happened, what about the last few years? Do you feel like that stress has kind of calmed down a bit?

Elaina: Yeah, I would say after my sophomore year of college, my stress level about evened out a lot because I got distance from my dad. Like living in the same house, you know, as your dad with a traumatic brain injury, it’s hard to process all that because it’s always right there. But being removed from the situation and I think me going off to college, me and my dad realized oh...that wasn’t forever. Like, she’s gonna go off and do things whereas like when I first went to college, my dad was like, “why don’t you go to Seattle” or you know, like all these places. And now, he literally asked me the other week...I was floored...he asked when I’m moving back in state. And I’m like, this is the man who was always like, “go...don’t stay home...live in another state.” And I think now, he’s kind of coming to terms with what’s going on. And a big part of that is, the people he’s around...now around with friends and coworkers who are just really good examples. So like, when he was in the hospital, his coworker Jack, just a great Godly man, like, goes to seminary while he’s at work, and just always praying for dad. Just showing him what a good father is supposed to look like...has completely changed our relationship. So like now, he’ll actually call me and we’ll talk on the phone and hang out...and I completely forgot what the original question was now! I just...free thought!

WL: I love it! I’m learning a lot here, because there’s...I think everybody needs somebody to like, model after, especially in a situation where like you said, you didn’t have an example of what a healthy marriage was. We’re trying to break these generational cycles and that’s tough, because there’s nobody around to help.

Elaina: Yeah!

WL: So we talked about how you felt during the experience and right afterwards, you said you bottled things up emotionally and internalized. And then, here’s a question: Did you have, even though you might have bottled it up, did you have any opportunities to discuss how you were feeling with your family?

Elaina: Yes. Yes, my mom did a great job. We would have family meetings and we would...we all got on the same page but she would intentionally make space for us to talk about things. So, it would be things like, every year before we would start school, she would do something special with me and my brother. Like, I like to go to this little tea house she'd take me for lunch and we'd have tea. She would always kind of open up the space for it. But, you know, you're in fourth grade. You don't know how to regulate or talk about your own emotions. So there was that. And she did take us to family therapy and so went as a group and then we started going individually but once again, you tell a fourth grader you're giving them homework (rolls her eyes). I am not doing that! So I remember going in thinking, I am not going to give this guy an inch of what's going on because, I just...I didn't like him. I don't know why. And I'll be honest, I don't think it was him at all, I think it was me. I think I did not want to address what was going on. Because it was so much easier to bottle it up. So I did have space but at that point I think that I had made my decision that I was not going to talk about it.

WL: Yeah.

Elaina: And, which is why this whole thing with my dad in February hit me like a ton of bricks because you know, I am trying to not bottle things up and healthily manage things and I was a complete mess. Like, it did feel like I was grieving something because it would just come in waves and I couldn't help it. So definitely have been trying to work out of that.

WL: Yeah, wow. And then, I think you answered this question. You are trying to be more open about how you're feeling emotionally as far as dealing with the stress. There could be some bottling up still but you are trying to be more like, getting it out there would you say? Or...

Elaina: Oh. Um, you know, I don't know that is necessarily it, but I don't think my mom ever said that, "hey this is how I'm feeling. How are you feeling?" Because, I'll be honest with you, she was going through a lot and it would have been a lot to open up. You know, where my brother also completely shut it down and at that time, my other close family members that would have been really nice to me, they did not understand what was going on, like...they just, they were good. Like they would try to help out, bring us dinners, things like that, but when it comes to the emotional side of things, they're like...I'm outta here. I don't know. Like, could not wrap their heads around what we were doing. Or what was going on. Any of that.

WL: Kind of feels isolating a bit.

Elaina: Yep.

WL: We kind of talked about how things leveled out in middle school and high school.

Elaina: I'm a bullet point person, so I would sum up that the reason I did so well in middle school and high school was because I got connected in with a good healthy, like social group of people that I don't think I had necessarily in elementary school. So, I started getting in my youth group, I had friends there. Then I started getting into art classes which I really enjoyed. I think I had more purpose.

WL: That makes a difference.

Elaina: Yeah.

WL: Looking back since the injury or surgery, how would you describe your life now compared to then?

Elaina: Oh man, like before the surgery...

WL: I know it can be kind of...you were so young then.

Elaina: Yeah, I would say, it's just so weird 'cause it's kind of...choose your own adventure. Like, if that surgery did not happen and he stayed healthy...I mean, he would still have, suffer from seizures. Let's say, without that, it was just...I feel like I would have had a much better relationship with my peers. And more, I guess, confidence? I didn't realize how much I struggled with confidence until, like honestly, the past year. So confidence was definitely...I think it had a lot...it came out as more...it would kind of swindle. I went from fourth grade, I had no confidence. I wouldn't do anything. I think I overshot into pride? Um, definitely overshot that one a lot. And then, got really humbled as soon as I graduated college! And then, I'm having to kind of rework that.

WL: Got ya, okay.

Elaina: But I would say, I think I just had healthier relationships with people, because people don't really know what to do when you say your dad has traumatic brain injury. Or, because your dad can't drive because of epilepsy meds, you can't...they don't know how to go about that. You know?

WL: So, you said you were pretty confident before that. That one year, maybe, it was kind of like the jolt to the system?

Elaina: Yeah.

WL: And you kind of leveled out after that. Makes sense. What about this? So, since that surgery, do you think your life has improved or gotten worse?

Elaina: Oh man, okay. Definitely improved. You know, because I was kind of rock bottom. It has improved a lot, because I have learned how to kind of process, like, things that are going on around, you know? Like, negative emotions. My relationship with my dad has gotten a lot better but it didn't look like a straight, "you know, we're getting better!" It was like one of those roller coasters up to where we are. But it's improved, because my life circumstance. Like, getting out, getting some kind of independence. You're no longer relying on someone you have a bad relationship with. You know? Where I can choose when I want to go to him to talk about something. It's not because I need help with school or something like that. It's hey, I actually want to hang out with you because I want to hang out with you.

WL: Right.

Elaina: That has helped, getting some sort of independence. Which is definitely one thing I've realized in the past year, is how much I value independence with myself and other people.

WL: Yeah.

Elaina: Like, you need to do it for yourself because no one is going to do it for you kind of thing. Because that is kind of how that went with my childhood. So my relationship with my dad has actually gotten a lot better. My relationship with my mom has always been really good and then it kind of waxed and waned a little bit because you start to realize your parents as adults. Like who they are as adults. Where I was very much...I knew my dad's flaws, it was very obvious. As a kid, where I idolized my mom and put her on a pedestal. And then, you become an adult, and you're like oh...you do have flaws as well. And ironically, since we're the same, they're my flaws too so I need a minute to process this. But now, we're in a pretty healthy place. So, all those kinds of things.

WL: That's easy to do, because your mom and your dad or whoever, that's who you model yourself after. That's...where you learn. You don't really learn by what they tell you as much as you learn how they act. And then you're like, oh, okay...my mom acts a certain way and then I do the same thing, I'm like no! No! So, rounding through the end here, there's a couple more questions.

Elaina: Ok.

WL: In your opinion, and there's no right or wrong answer, how well do you think you've handled the brain injury or the surgery?

Elaina: Oh man! Ok! [laughs]. I don't know. I, I...see, part of me is saying, well I handled it pretty good because you know what? I survived! You know? Like it really is a response mechanism to stress and like your body thinks, oh my gosh, my life is on the line. That's how you're responding. So hey, I survived, and I didn't kill anybody, so! I think initially, it was not a good healthy way to handle things. Like, I completely internalized it. But, how else is a fourth grader going to respond to that kind of thing? I think I...I'm proud of myself of how I have processed it later. So, in college, as hard as it was, it was really really hard...I finally unloaded it all and processed it. And I am proud of myself for kind of doing that and taking the time and the space to do that. I think it was setting me up for the future because now I don't bottle stuff up. When it happens, I may cry, but I'll get through it! And it'll be okay, and so much better than bottling it up.

WL: Yeah.

Elaina: So, originally, I give myself like a two out of ten. Not healthy, not great. And now, I think I moved my way up to like an eight out of 10.

WL: Yeah. And that's totally fine, because there's no right way to handle them [brain injuries] because they're so unique, right? And this is going to sound interesting, but...do you think you went through a difficult time in that experience? So, I know you said you survived at first and you internalized. Would you classify that as, like, that was a difficult journey to this point?

Elaina: Oh yeah! Yes, it's like climbing Mt. Everest. You get a couple of areas, where you're like...well, I have never climbed Mt. Everest, maybe I shouldn't compare it to that! But climbing a mountain, because I have done before...and there are sometimes that are very strenuous and hard but you have other times where it kind of levels out and you can kind of enjoy the view and appreciate how far you've come. Because there's the process of, okay...I had to process what happened, like that ever going grief, but my dad changed into so many people. My mom always jokes that she's been married to five different men because of how my dad has been. And so, right now, they're in a good place because my dad can help lead. Like, respond to things and is caring and you know, it's funny...before, I never wanted him in my wedding. He was there, but I didn't want him to walk me down the aisle. I didn't want the daddy daughter dance. And now, we're planning what song we want to do our father daughter dance to. So it's funny how it just kind of comes around and we can kind of build off those things once you kind of process things.

WL: I love that mountain analogy. Ok, so here is the closing! If you had to offer advice to a kiddo who was going through something similar, what do you think you would tell them?

Elaina: Oh my gosh. Ok.

WL: Impart your wisdom!

Elaina: Ok, there's a couple of things. And, I'm going to give credit to my mom for this one. You have no idea what other families are going through. They may be perfect on the outside. Perfect. But, things may be falling apart on the inside, so don't necessarily get jealous or envious of what they have because you really, truly never know. Because I think that was an issue for me, because I would be looking at these other families in church...perfect matching shoes and all. And, you grow up and you learn, that was not the way things...everybody's got their struggles.

WL: Yeah.

Elaina: I guess the other thing would be...find something that you enjoy that helps your process it. Not everyone likes to sit in a room and talk to somebody about how they feel. And that's okay. That's good! I would encourage you. I think that's sometimes the most healthy way. But, find a good healthy outlet for it. It could be sports. It could be...for me, it was drawing. Something that you enjoy that can help you process it and find purpose in it. And connect with other people and find your community. Which I think is kind of good advice for...no matter the trial or what you're going through.

WL: Yeah. That's good advice! Okay. What about this one? Is there anything you would change about your experience?

Elaina: Oh man [takes breath]. I kind of wish I could delay the timeline. Like I wish I had a couple more years with my dad before the surgery. Because I won't say I necessarily...obviously...I would never wish pain on anybody, but sometimes I wish it didn't happen because it helped me become the person I am...but I wish I had more time with my dad before the surgery.

WL: I understand that. Last one! Is there anything you want to add? Anything we didn't cover?

Elaina: Oh man...I know I gave you like a novel's worth.

WL: No this is great!

Elaina: Not really. I think, just going back to the sum it up thing, I think finding...because for me, it was finding a community of faith in that youth group, that was important. Just like, you're never going to find someone with a similar circumstance but if you can just find people who you feel like are empathetic and will share part of their story as well, it's really helpful.

WL: Yeah. Awesome. Look at that!

Elaina: Hey we did it!

WL: We're done, yay!

### **Elaina Second Interview**

WL: Alright, so...I got everything transcribed from the first interview but I wanted to follow up with you. I know you said you saw your dad change after the surgery happened. So like, summatively, what was the most difficult part about the change that you experienced?

Elaina: For me or for him?

WL: For you.

Elaina: For me, I think it would be seeing...you kind of idolize your parents as adults and everything. And then, umm...just seeing his mental capabilities just dramatically decrease. (I) was a big like, oh my gosh. That was the initial. And then after, I would say the first year, it was more of the emotional. Like, he was not the same guy, would not respond the same way emotionally to things. It was kind of a twofold. The first six months, I would say: oh my gosh, he doesn't know what a remote is. And once you got past that, his personality and mentally...not the same. If that makes sense.

WL: Yeah, absolutely. So, let's look back over the years since the accident...the surgery...can you look at anything in your life and say definitely, ahh yes. This is because of my experience with my dad?

Elaina: Oh, like something I did or a choice I made or something?

WL: Like a choice, or a situation, like I know we talked about you became a teacher for some different reasons. Anything you can look back and say, because my dad was injured, this happened.

Elaina: Yeah, that's a good one. Umm, man...oh man.

WL: I know I just threw it on you there.

Elaina: I would say becoming a teacher is the most direct. [pauses]. I guess that, well...that's a good one. I am trying to think.

WL: Take your time, there is no rush. If you say, let me think about that one, you can send me an email later on and let me know.

Elaina: Okay, we might have to. Let me write that one down.

WL: Because, what I am looking at...one of my research questions is, how does this idea of ambiguous loss, this loss that isn't clear... does it result in any kind of tangible consequences later in life. So the teacher thing is great because it helped you choose a career and that's something tangible.

Elaina: Yeah! So are you looking for something tangible?

WL: It can be, yeah. There's really anything. I am trying to see if there is a connection.

Elaina: Well yeah, it's one of those questions where it's like, there's nothing to hold it up against ya know? So, trying to get to those factors of why...I would say I think because it shifted the family dynamic so much, it changed how I make decisions as a teenager and as an adult. I am very much a perfectionist, I am a go-getter type of person, so I don't sit around and wait for things to happen. I go, I'll jump in and be the leader. When the family dynamic shifted, I felt like I needed to take control as the older sibling of the family, things like that.

WL: Yeah, okay...that's perfect. You know, kind of like my deal with...I wouldn't be researching TBIs had I not lived through it, so that is something tangible that happened to me and it's just different for everybody, you know?

Elaina: Yeah!

WL: Okay, that's cool! So, let's think about this idea of loss real quick. Do you think you experienced a loss of any kind through your dad's injury/surgery, even though he didn't pass away? Was there a loss there?

Elaina: Absolutely. And I will say it's...my mom uses the best analogy where it's like, it's been several different men. It's the same guy, I promise! But they respond differently. I have different relationships with my dad at each of those stages. But it was definitely kind of grieving that, like

I'm not going to have a normal dad and he will never be the way he was pre, what was that? 2008? So yes. But that being said, I feel like the dad I have now is the closest I have ever had to a normal dad. Thankfully I do get that relationship that I never thought was imaginable before.

WL: Yeah, that's so cool. And then, so...with that idea of less, like: yeah, there is a sense of loss. Do you have any inkling of how that's playing out in your life today? Is that sense of loss something that is prevalent and kind of, front of mind? Or?

Elaina: Oh yeah. Well, it's one of those things where it almost feels like its baggage because I don't know...February of this year was very jolting because it's like, I want to really invest in this relationship, but one: you don't remember my childhood for the past 15 or 20 years. Second of all, there is this kind of like...what if you lose it again? What if something happens? And then, how invested am I going to get in this relationship with someone who might not stay the same over the next five to ten years?

WL: Yeah.

Elaina: And I definitely felt weary when my fiancée' met my dad. They have such a great relationship, but I kept thinking...I was on the edge of my seat, like...oh my gosh. But like, what if something happens? And he also has to go through that process of loss as well. Both me and other people that are close to me, coming into the family.

WL: Yeah, yeah...that can make it pretty uneasy because you feel like you are always on these shifting sands, kind of. And things can change in a second.

Elaina: Yeah!

WL: Ok. So, I know in our last interview, you mentioned at one point that it felt like you were grieving...something. I think it was back in February when your dad fell ill again on the plane. Can you expand a little bit on that feeling you had? Or maybe just expand on that grieving part?

Elaina: Yeah! Besides my...I mean, it's not like that wasn't enough as a kid...but besides my dad's event, I did not experience any other true loss, you know. My parents didn't go through a divorce. I had like a, far off uncle die and I didn't know how to process those feelings. So I am very thankful to have never been that close to immediate grief to know what that looks like. And so I feel like my experience in February was the closest I had ever been to like...not, essentially losing a loved one. Because, you're right...there were those shifting sands of we didn't know what the turnout was going to be like, what that was going to be like. So, was he going to survive it? Survive it with a lot less capability, what that was going to look like? And it was just like a...I'm not diagnosed with depression and I don't want to use that term, but like, just a dark cloud of lethargy almost. Not wanting to do anything, on the verge of tears all the time. And I couldn't focus on anything in my life, it was just so scatterbrained. And I couldn't work well, couldn't teach well. And that lasted about two or three weeks, until when he had gotten out of the hospital and there was a little bit more evidence that thankfully, he had almost a full recovery.

WL: Yeah, okay. That's what I thought it was but I wanted to expand on that just a little bit to make sure I was going to represent that correctly.

Elaina: Yeah.

WL: So, just a couple more here and you are good to go. I know we talked quite a bit about your family in the first interview and so...maybe in like, a few words, can you summarize how you viewed that family unit before the surgery happened? Like, my family was what?

Elaina: It was like a weird Thomas Kincaid painting, you know? Everything...it felt very like, nuclear family. And once again, I was a lot younger, so I think there was rose colored glasses when you look at it. But everyone, I felt like, was on equal standing with each other. Like I had just as good a relationship to my brother as I did with my mom as I did with my dad. And after 2008, it felt very divided. It was a team of three versus. a team of one. And I think even though my dad may not remember specifics or memories from that, I feel like he still feels that divide still to this day.

WL: Yeah. And then, I want to go to the same thing here. We talked about how you viewed yourself before. You know, in the elementary grade levels, you were like super confident and the go-getter! And afterwards, we talked about that transitional phase in the fifth grade and then the college years. We covered the whole gamut. How about today? How would you describe yourself with the full experience you've had from being super confident...surgery...post-surgery and all the way up through college and then the February incident with your dad. How would you describe, in totality, now.

Elaina: Oh my gosh, umm...definitely still a sense of responsibility. But in the past couple of months, since he's been doing so well, I've kind of felt less pressure and that role. But even as...while I was so much more of a go-getter, I think I still do have that. I am more...I don't know, I'll say chill about things. I don't jump on and say, I can do it! [laughs]. Let someone else do it then I will do it! But I definitely feel that my role as feeling like a caregiver was most intense in middle and high school. Where I think, moving away and going to college, moving to another state, has definitely lessened that a lot. And my dad has also just become, thankfully, so much more kind of capable and less on edge and needing less from us.

WL: Yeah, and that can definitely change things. Okay, I am thinking we might have covered this but I want to touch on this real quick here. Did that experience with your dad, did that shape your self-image in any way?

Elaina: Oh absolutely, absolutely. I think it changed how I value myself. So, I need to be useful in order to feel valued because there was a lot going on. It was kind of...and I'm sure you can relate to this, like selling my mom as a single mom but also like with a parent who is also a kid? My mom always jokes that it feels like she has three kids! Because, essentially, he is the third child in that. And so, I felt like as the oldest and most capable, second most capable person in the household for over a year, even though I was in fourth grade. I kind of felt...definitely the role of caregiver, a lot of responsibility. Even though I know my mom did her best to make sure us...for us to not feel that way, but there was a lot of stuff to do and definitely falling into that role.

Umm, still to this day, I do feel a lot of value in feeling useful and kind of the manager of whatever job, relationship, situation I'm in. I need to feel useful and like a manager.

WL: Yeah that makes sense, and it looks like it has carried over from you went through because you kind of had to grow up a little faster than other people, I would imagine.

Elaina: Yeah.

WL: Okay, and my last one here. So you grew up...your story is unique in that you grew up with a brain injured dad, kind of from birth. We talked about comparing and contrasting, but that's kind of all you've known, having an injured dad. So I am trying to get a sense of...how do you view that situation. Your dad is brain-injured, it's how it has always been. Do you view your situation as a good thing? A bad thing? You know what I mean?

Elaina: Yeah. Well it's funny. When you compare one to the other. So, you know, I think if his surgery...his seizures had not gotten worse to the point of surgery, then that would look pretty bad compared to other people without someone with a TBI. But, knowing how much worse he got, like, personality wise after the surgery, then the seizures didn't seem so bad. And now that he is somewhat normal, and he has all these new seizures...now this would have been nice for 25 years! But...how do I want to put this? It's kind of like the baseline was very different and unique, like you mentioned compared to any other person who had the traumatic brain injury and their life changed. I thought everyone's dad had seizures, I thought that was just standard with the unit that it came with? You know? [laughs]. That everyone grew up with that, almost like a cultural thing in a way.

WL: Yeah.

Elaina: Does that answer the question? I feel like I might have veered off.

WL: No, I feel like your situation is like, it has always been that way so that was kind of what you grew up with and the perspective you have is different. If that's all you know, that completely shifts the perspective. It's still difficult, just a different perspective.

Elaina: And I know you mentioned the good or bad...I never viewed it one way or another. And now that I am older and I talk to people whose parents have other health problems, diabetes or other things...it just kind of feels like the card that was handed to us. Like, people are handed a different card, whether that be a divorce rate or whatever that is. Just kind of, our flavor was...unfortunately, a TBI.

WL: Yeah, well hey, that is it! I don't want to you any longer. That's all I had for you!

Elaina: Awesome, thank you! Good luck!

WL: Thanks, bye!

### Paul First Interview

WL: How old were you when your parent had their brain injury or, the surgery?

Paul: Umm, it's either 2008 or 2009, so I would have been eight or nine. Uh, it really doesn't have to do a lot with it, I just know...I think 2009, because 2008 my dad had hip surgery replacement, and that kind of entices, because it was back to back to back to the hospital you know? But I think 2009, so I would have been nine.

WL: Okay, and...what grade were you in then, do you recall?

Paul: Elementary school, you know. Mid-range elementary school.

WL: Okay. And then, can you tell me how your dad received the initial injury and then anything about the surgery?

Paul: My dad originally, umm...had epilepsy. He had a seizure tissue on his short term part of the brain. But he's also had head trauma, I think that was '94. 1994, he fell off a ladder and got electrocuted so he has had a lot of head bangs but from what I have always gathered, the seizure tissue was just there from forever. It really wasn't there from like, an injury. But I don't know.

WL: Got it, okay. And, did they ever tell you or did you ever know if the TBI was classified as moderate or severe?

Paul: No, I mean...if I could label it in my terms, I'm not a doctor, but I'd say probably severe just to the extent of the effects.

WL: Mm hmm, absolutely. So you were...maybe nine years old back then. So what was your...I guess it was a little different. So, your dad always had the injury since you were born, right?

Paul: Yeah.

WL: So the surgery, was that something that happened that kind of changed something?

Paul: Yes, absolutely.

WL: And, do you remember having a reaction to that? After your dad had the surgery?

Paul: I wouldn't say like, a direct change of black and white immediately. But, I noticed over a period of time a change. Like, for me at least, our relationship had grew apart after the surgery. It wasn't immediate, but it definitely changed over time.

WL: And when you saw grew apart, do you have an examples of that?

Paul: He would become very hostile and I would kind of...back away. You know? I'm always a mama's boy, but I really started to really lean on her whenever I needed a parent.

WL: Okay, and so...he was kind of more hostile and you backed away a bit. Do you remember feeling any emotion as that was happening? As you are thinking of it in real time?

Paul: During the surgery? After? Or like afterwards?

WL: When you realized your dad was kind of changing a little bit, did you experience any emotion during that?

Paul: Yeah, umm...I felt almost hostile towards him. And kind of, as me being kind of a young teenager, and you know...before that, just a kid. A teenager. Kind of standing my ground and fighting that, you know? He didn't take all his meds and I do know that the medication he was on, to help his brain, could...would make him more hostile. But, he wasn't taking the medicine to counteract that part so he was only taking half of it which really is a huge part of it. And, he would basically become hostile, and wouldn't...he couldn't understand that he was actually doing that for a very long time.

WL: And now looking back, now that you are older, do you blame your dad for acting in that hostile way or how do you view that?

Paul: I wouldn't necessarily blame him. Him and I are very much the same, very hardheaded. So almost everything I saw him...from where he came from, even though it made me angry, I saw where he was coming from and I wouldn't label it one hundred percent his fault but I wouldn't say he's scot free on this.

WL: Right.

Paul: I give him some blame, but I know it's not all his fault.

WL: Let's talk about before the surgery. What was your family life like before then?

Paul: I don't have a lot of memory off that but I do know...my mom very vividly remembers that my dad was very good with us. And I see that in the way he treats other younger kids. For whatever reason, even afterwards, he's just really good with younger kids. I'd say, like, anywhere from like, the ages of 7 and earlier, he's just really good with them.

WL: Yeah.

Paul: With cousins and kind of, neighbors kids, I just know that he's really good with that. So I think he was really good, you know? There's a lot of picture of us just having fun and whatnot, so...

WL: And when you see that...I know you don't have a lot of memories, but when you see him being really good with kids, does that bring up anything for you?

Paul: Yeah. There have been times when my cousins would come down and visit and he would always treat my sister and I unfairly compared to what my cousins got. It was like, we were always held to a higher standard. I know they were guests but he would always go above and beyond to make it ridiculous. You know, it was...we were never perfect. Like, he never told us he was proud of us but basically, family would come over and they can do basically what they want to the house, and he would be happy that they were there, so...

WL: Yeah, and you would be standing there like, well!

Paul: Yeah, it just wasn't...it never felt fair. You know?

WL: Yeah, for sure. And then can you tell me how you were academically before that? I know it was elementary school, but do you think you made good grades before that happened?

Paul: Yeah, I really don't think that whole situation affected me academically. Uh, I guess I was always an A/B student and I have always been, and so...

WL: Okay, so no academic struggles from the surgery, you don't think?

Paul: Not really. Maybe if it happened later, possibly. But, it was a younger age and I don't want to say grades didn't matter, but I never noticed a difference with that.

WL: And then, you talked a little bit about your family life before the surgery. How was your relationship, let's say with your mom, before the surgery?

Paul: Really good. I don't think my mom and I's relationship...we're very close and I don't think it's really ever changed, period. I think we've been really strong together and that's how it always has been.

WL: And what about your dad before the surgery?

Paul: Um, I'd say we were close, it's just hard to remember. I'd say we were closer I felt like...I do remember before, I could feel like I could tell him something. But even...even now, I feel like...like even today, there is some form of space and I really don't have interest in telling him because either the way he reacts or you know, either doesn't care of he would just react hostilely (with hostility) if I asked him if a friend could come over. He would always just be like, no. And just...I never cared to deal with that.

WL: And do you think that is something that stems from everything that's happened physically and to the brain and all that stuff? Or you said, maybe partially him a little bit as well?

Paul: I'd say both.

WL: Okay. And then, what about your sister? How was your guy's relationship?

Paul: Between my sister and I?

WL: Mm hmm.

Paul: Good. Her and I grew up and we fought a little, but I mean...I'd say as most siblings have. I'd say middle school and high school, we fought the most and after she left for college, we got closer.

WL: Yeah.

Paul: But I don't think from his injury that our relationship really changed much.

WL: Okay.

Paul: From the...our dynamic relationship...that my dad's injury did not have an effect on that.

WL: And how did you view your sister when everything was happening? Was it still like, that's my sister or did you look at her like a leader of the family helping out? How did you view her at that point?

Paul: Just as my sister. Um, my mom...my mom has a medical background so she always really took charge and when someone has a medical injury, or something, she knows everything, all about us. So I would say she really took charge in any aspect with the injury.

WL: Okay, so your mom was kind of like the caretaker.

Paul: Yeah.

WL: Yeah. Ok, um...and what about your relationship with other people during this time with like friends or whoever it might have been? Do you remember anything about that?

Paul: A little bit. I really don't think it ever affected that too much.

WL: Okay, no effect on the friendships. And let's talk about you before the injury. So if you had to finish this sentence...how did you view yourself before the injury. So before the injury, I was what?

Paul: Happy, I'd say I was a kid, you know? Growing up on the lake, I enjoyed...life.

WL: Yep. And then, right after that...well, it doesn't have to be right after that. So, before and after the surgery, did you notice anything in your behavior that changed or shifted at all?

Paul: I felt like overall, I viewed life a little more hostile. Not...I didn't view everything as hostile but I noticed slight changes on the way I viewed things.

WL: And so, you viewed things more hostile. Sounds like a negative thing more than a positive

Paul: Yeah.

WL: Um, what do you think that means? Like, you viewed it hostile?

Paul: I'd say hostile...I guess a more realistic look you know? Accounting for those factors. Um, I guess just viewing the situation as more of a reality instead of just like, being happy all the time. You know?

WL: Yeah, like you are going through stuff that's real?

Paul: Yeah.

WL: Ok, before then...you said you were happy and then you might have been a little more hostile towards life, that makes perfect sense. And then, right after that happened, the surgery...can you describe what your experience was, those first like few months to a year?

Paul: I really don't remember a lot. It's, I think...with back to back to back injuries with his hip surgery and then his brain surgery, it's not really...I don't want to say it blurred, well I guess...it was a blur because it just kind of combines into one and it was a lot of...just like, it went by so quickly but felt so long at the same time. You know? I guess if you looked at it as like a...map of my life, it just feels kind of a blur.

WL: And what was going on during that time that kind of made it like that? I know there was a lot happening. Were your parents gone a lot or were there lots of visits to places?

Paul: They were gone. They had to go to Winston Salem because that's where he had his surgery and everything done. They were gone every so often and a lot of physical therapy and a lot of that but, I don't think that really impacted too much. But, that's all I can really remember.

WL: Yeah, that's totally fine. Ok, next question. You said...there were some changes in your dad you noticed.

Paul: Uh huh.

WL: Right? I think hostile came up quite a bit. Let's talk about a two-fold thing here, so mental and emotional. Did you notice any mental changes in your dad after the surgery?

Paul: Absolutely. I'd say for a long time, like I said hostile...he would...he would get very angry at something and just kind of like, focus on it...to like a crazy extent. For example, if I wouldn't pick up something, that would basically turn him into a train wreck, and he would just kind of go nuts over it and just like, not even...it's someone you would even want to be talking to when that happens. You know, you just kind of...you want to get away. It...and...it took him such a long time to even...for him to realize. I mean, it took him years for him to realize that he was doing it. And while he's doing it, he doesn't think he is doing anything wrong and he thinks he is justified.

WL: And does that feed into the emotional status of your dad as well? Did you see anything emotional there? I guess the anger...

Paul: Yeah.

WL: Yeah. Anything else that was noticeable that you can recall?

Paul: Yeah I mean, part of the surgery...the tissue was really part of his short-term memory and he...I have short term memory loss and ADD, I was diagnosed with that even though I didn't have any part of my brain removed, and he did. And, he really cannot remember stuff. He already had a memory issue before that and then take out the short term memory, he really cannot remember things. And so, and that goes kind of into play with not knowing that he's doing something...he gets angry with something and doesn't realize he's doing it and you know...it's just a spiral.

WL: Yeah. And what about physically with your dad, after the surgery? Any changes you saw there, anything he could or couldn't do?

Paul: I guess I say that...he's had a lot, more physical surgeries. Like his hip and his arm and other things that have limited him more. I don't remember any physical limitations but I do know his balance has always been awful. I don't know if that really corresponded with that but he is very very...not stubborn, stubborn is the wrong word. Very...uh, doesn't give up. I don't know the right word.

WL: Strong-willed maybe?

Paul: Yeah, very strong-willed. That's the word. Very, very strong-willed. And this is a compliment to him, uh...anytime he goes through physical therapy, it's crazy the things he can do through his...basically, his sheer will to push through.

WL: And all those physical injuries, did those stem from the initial fall and that electrocution that he went through?

Paul: No, I don't think so. He did have an incident...I don't know if my sister talked about this. He did have an incident in Colorado...I don't know how long ago you talked to my sister. He had four grand mal seizures on airplane. Oh no, two more on the airplane and four on the ambulance or vice-versa. But, he was in the ICU for a week. The day he got in the ICU...or the day he got out, a week later he was filing his taxes. So that's what I say, like, his sheer will to do something. You know, but, I think it's kind of hard to judge because it's such a collective...you know, amount of injuries. For me, I'm not a doctor, I can see how...it's hard to really diagnose what is affecting what because there is so much damage.

WL: Just a lot going on.

Paul: Yep.

WL: Yep. And then, I kind of talked about your mom and your dad and your sister before that. What...did you guys experience any changes as a family unit after the surgery? Anything you can recall?

Paul: Yeah, um...and, I'll put it in my dad's word. My dad would always say this...he always felt like an island. He would get upset because he felt like, at the dinner table, you know, he felt like an island. It would be us three versus him and he didn't feel included and I feel like us three got much closer and not necessarily trying to push him away...but, I think part...I think we kind of slowly pushed him away and also, he pushed himself away too. I think it was just a collective...but he blamed us for it. But I think it was a matter of him just struggling and he couldn't comprehend. And, life is going at, we'll say...100 miles an hour and he can only go 60. And it just, he just can't keep up.

WL: Yeah. So, you guys have isolated as a group and he isolated a little bit himself.

Paul: Yeah.

WL: The divide, yup. And then...how do you think that experience with the surgery...how did it affect you personally, looking back now that you are almost in your 20s?

Paul: The surgery itself?

WL: It could be the surgery or growing up with a brain-injured dad.

Paul: Yeah, um...it definitely makes me look differently. For example, my girlfriend's dad and I are very close. Even though I don't live with him, I talk to him more than I talk to my own dad. He likes the same things that I do, we're both into cars. I'm currently building a '67 Mustang and it's...we connect on that, you know? I mean...him and I text every other day but my dad says he wants to be a part of it, but doesn't try to...learn anything about it or do anything and...he built some old cars himself too, in high school. He built a '67 Chevelle in his driveway and I ask him questions about it and he just doesn't seem to care. You know? But he will blame me for not wanting to include him. So it's almost this, catch-22. That's one of the biggest things. I would say he does a lot. He...he blames you for not including him but he pushes away, and I don't think that...I don't think that he knows he is pushing away, he's just being realistic himself.

WL: Right, so you're having to...you've got a dad but you might be having to try and find like, a father figure somewhere else.

Paul: Yeah.

WL: To kind of fill the void, perhaps.

Paul: Yeah.

WL: Yeah, okay. And then, now that you are an adult, do you think the injury or the surgery...do you think it's going to have an effect on your professional life? Such as what you choose to do with your career or?

Paul: Probably not, you know. I don't think it...I'd say after the injury, I guess I'm just starting to remember things as I talk about it. After the injury, I really...I don't want to say closed it off, but I sectioned it off. I kind of, you know...I remember, for my birthday, we went down to Florida. Orlando. And, we stayed in a Hyatt hotel and I...my memory always served that it was a good trip but my mom tells me up and down it was an awful trip. My dad was terrible you know? Complained the whole entire time, you know. Just being as difficult as he could be, but I...I don't remember any of that. But, you know, that was such a long time ago. That was like, a couple of years post-surgery. And so, I know for me I've really sectioned everything dealing with him. Not him himself, I don't push him out the door, but I try to section of the affects that the surgery had and try not to include it in my main life decisions.

WL: That makes sense. What about, now that you are an adult. What about your family life these days? What's that like, with your mom and sister?

Paul: My sister is living out of state so we talk once in a blue moon. Uh, because she's just getting a new car so her and I are talking a lot. But, really...he works a travel job and so when like...my sister has been coming home a lot of weekends, but most...I'd say half the year, it's just my mom and I. And her and I have our rhythms, we have our, you know...our things we do every single day. And we stay in that rhythm. I come home, I talk to her and basically we go to bed. And when my dad comes home, he...my mom and I do get frustrated and it's really the same thing when my sister comes home. We get frustrated when somebody else comes in and kind of messes up that system but with him, because he's home half the year...he gets upset that I don't talk to him, when, you know...I'm so used to just going to my mom. And I do know that when I talk to my dad, I'll go home and just need to vent about work or just something simple that happened in my day. But at the end of the day, it's not gonna affect, but I just need to let it out. But he will talk to you and try to...he won't let you talk about the bad and will only want to talk to you about the good. So, there's no way of getting it out because it's not an argument but it's almost like...somebody opposite of complaining almost. It almost seems like he doesn't want to talk to you but he's just trying to, you know...I don't really know what he's trying to do, but it's kind of frustrating because you are just trying to talk about your day and what happened and he's always just like, "well let's hear something good...let's hear a story" when you don't really want to, you know.

WL: Maybe like over the years, it's kind of built up...

Paul: Yeah.

WL: Kind of like, that ship has already sailed. Okay, do you think the injury or surgery affected your personal life in any way? Like relationships with others or

Paul: Yeah, um. A lot of...my best friend and other people have no...my best friend who I've known since third grade, I've been best friends with him before and after the situation. And, part

of that...you know, he (dad) barely remembers his name. His name is Ryan. You know, but I don't blame him (dad) for not knowing his (Ryan) name but with him (dad), it's kind of a struggle to sometimes talk to him. And whenever he (Ryan) comes over, you know, he'll (dad) kind of barge in and he's not mean, he's just trying to have a conversation. But he stays there forever and ever and ever and just keeps talking when him (Ryan) and I are trying to do something. You know, and of course I sit there and feel bad trying to kick him out, you know. But I definitely think between other relationships that I have, he tends to nowadays barge in and sit there. But I feel bad kicking him out because he always talks about trying to be included. So I really try to, you know, let him be happy.

WL: Okay, tough stuff. How do you think your stress level has been impacted from the surgery to now? Do you think you are less stressed, same stress, more stress?

Paul: Overall?

WL: Uh huh.

Paul: I'd say...a little to medium amount. I'd say, if I'm away, I don't usually worry about it. I tend to only stress about things that are kind of in front of me or if like...for example, I've got a homework due date and it's really off on me, that's when I worry about that. If it's right there in front of me. But at home, I get almost stressed to live...almost anytime it seems like, to a certain extent, if I am around him or something there is some sort of stress. Where if I am with my girlfriend or my best friend or my mom, I don't feel that, you know? Cause it almost feels like, growing up with him, maybe that aggression that he had...it's almost like, you know, you grew up with such...him and I...he never hit me, but growing up, if he did...and he stops cold turkey one day, you still kind of think that oh, he might hit you. You know, it's still there. More or less of he might just get very hostile even though he really doesn't these days. But it still lingers.

WL: Still in the back of your mind?

Paul: Yeah.

WL: It could come back.

Paul: Yeah.

WL: Okay. So, okay, that kind of answered the next question as well as to how it might have increased your stress a bit, that makes perfect sense. Okay, are you in school? You said school, where do you go?

Paul: I just graduated from the local community college (name omitted for confidentiality) with a welding fabrication degree. In the fall, well I say the fall...in a month from now, I am going to university (name omitted for confidentiality) for mechanical engineering. My sister's fiancée talked me into it. He went to the school for six years and then his...what's it called? His professor. His advisor, he moved out of state so he said, let me just go and finish and he just graduated with Ph.D.

WL: Wow, there you go.

Paul: So, he really talked me into it.

WL: Yeah, well that's cool. I'm on your path, did the same thing you did. Okay, so...we already talked about how you felt when the surgery occurred so that's fine...when everything was happening, did you have a chance to talk about how you were feeling, like emotionally?

Paul: I went to a few counselors, therapists...if there is a difference. But...I never...maybe I never got out what I needed to. I think I really went because my mom said I needed to go. And I remember from the first one I ever went to, like for example...my mom would pay for the whole hour and all I would do was try to finish up so we could play board games. You know? And, you know, my mom...I don't really remember what she would say but at one point, she was just like, "is this really helping you, yes or no?" And I really just was like, "it's not." So she stopped and even today, going to talk to a therapist or somebody about it, it just...I don't see the benefit to it. You know? I've been to them before and I have been to different ones, maybe they just don't work for me. You know, but...really it's been my mom. Maybe it's that like, I know she doesn't judge me. I really don't have to come in with a background of a situation. You know? And...she probably understands me a good 95% of the time, you know? And maybe, just that making it easier. And if not, I usually go to my best friend because he also understands and those two people, I can...I can let it out, you know, and they don't judge me for it.

WL: Well that makes sense. Because, you are telling me your story and it's very similar what I lived through. But I haven't lived your experience so I don't know the full depth of the emotions that you might have went through. And then when you take it to a counselor or therapist, they don't know either. You have to bring them up to speed...

Paul: And it just...I don't know what it was, you know, a lot of them...I had a few that say they aren't judging but, boy...I can tell you they were judging. It's you know, nothing...a lot of...the one that really judged me wasn't anything even related to this. It's just...maybe I got a bad taste in my mouth. I just felt like, you know...a counselor is just not that.

WL: So, we talked about stress a little bit and kind of how, like...something could happen again that hasn't happened in a while with your dad. Do you think you handle stress differently now versus when you were younger?

Paul: I think so...I don't think between his situation and I that it really made that effect, but...I think it was more or less me maturing just in life. I learned to kind of break things down. With me, I'm like my girlfriend because I tell her the same thing: I see this tall mountain, this pile of stress, you know? If you're taking a bunch of classes and you have like, a bunch of essays due, I would look at it all, panic, and shut down. Where my mom always tells me, break it down and do one single thing at a time. And when I do that, I get through it. That's just, you know...but I don't think that had a correlation with my dad's injury.

WL: Yeah, that makes sense. A couple of more here and you're good to go buddy. So, academically you said you don't feel like the injury affected you much before or after...or, the surgery.

Paul: Uh huh.

WL: Okay. How would you describe your life now compared to before the surgery happened? I know you were younger and might not be as easy.

Paul: Well, I guess...I guess I'd say, you know, I guess when I look back on it...when I look back on that part before, I think it's just me seeing myself as a kid. Kind of, just...my backyard was a lake and there are pictures of me in the lake and in the backyard. There's one picture...I'm sitting in the backyard and my dad is sitting right next to me. And it's like, almost like the...the picture ending of a movie. Kind of picture. And I know it was not intentional at all, because it's my dad. And that I guess is the picture of every single time I think of before that time point of just me being happy and not really caring. But I think it was also a point in my life when you're just a kid where you don't have stress. You don't have goals in life, you just go and hang out with your friends because everything is fun. And nowadays, dealing with him is just one more thing, part of the pile. So, I don't know how...if I really...in my mind I think I don't really focus on it. That's one more thing on the shelf to deal with.

WL: Yeah.

Paul: So it's definitely there on the shelf, dealing with it but it's not...out of a whole bookshelf, you know, out of everything in my life.

WL: Makes sense. So, and this can be either before the surgery or immediately after, do you think that life has improved since then or gotten worse?

Paul: Much better. Well, I say better as of right now. I'd say it almost kind of was like...right after the surgery, it never went up it just seemed like a slow decline and then really fast decline and ever since then, it has been going back up and has never been the same. And I don't think it ever will for the rest of my life between my dad and I. But there was one point where I just know...when my mom would chew my dad out for kind of being his stubborn, you know, angry hostile self, you would just kind of...say sorry, but almost like, a definite sorry but you could almost tell he was not sorry. Just kind of like, whatever makes you happy sorry. And one day, he really was like, hey I am genuinely sorry. I think he realized how he treated us. So I definitely think it's...it has definitely gotten better. But I don't think for the rest of my life that it will never be the same.

WL: Yeah, because you kind of said, like...it's almost like the mountain analogy. The baseline changes every time...if this is where you started...

Paul: Yeah, you're never...it's going up and I don't think it's going to immediately crash. I hope it doesn't but I don't think it will ever go back up to the same.

WL: And how is your mom and dad? How is their relationship today?

Paul: Today? Good. Basically, probably the best it's ever been since 2008 or 2009.

WL: Okay, good. And then, in your opinion, how well do you think you have handled the surgery and the brain injury?

Paul: I guess I'd say. If I could right now, I would say "oh, there's things I could have done differently." But I know I'll never have the chance so basically I tell myself, I did the best I could because I can never change it. So I always tell myself, why worry about what you could have done better but you can't? It's all behind you. So, I also don't think I could have changed a lot you know?

WL: You think that's due to how old you were at the time?

Paul: I think so, being 8 or 9 years old, you're just there to go in the...2nd, 3rd, and 4th grade and just go hang out with your friends, so you don't really care about...I don't think I really cared about the whole life impact. I didn't even have a cell phone at the time.

WL: And then, let's say on a scale of one to ten with one being terrible and ten being awesome, where do you think you fall on that scale with how well you handled it?

Paul: Overall, I'd say 6 or 7. 6.5.

WL: Okay. I remember being nine years old and dad was off his meds...I remember being like, I'm 9 and I shouldn't be dealing with this. So the things you are saying makes perfect sense. The hostility and the rage, I've seen it.

Paul: Yeah, I just remember...I was in cub scouts growing up and I remember one time going to cub scouts and my dad just got real angry. And I just kept calling him dad and he wouldn't let me call him dad, he just kept telling me to call him by his first name. He would never let me call him dad and there were other things where my mom found him once...he got angry and I don't know where he went, but he went to some bar or something and ended up...oh, I remember. He went to some bar and came back. Our neighbors, who have been our neighbors forever, they used to have multiple houses so this was their small lake house, so it was their getaway house. And, it's of course torn down now. So, my mom found him over in their old house before they tore it down in there, like, overnight. And my mom chewed him out for doing that. And there was a lot of times that were like that. He was just kind of, couldn't handle it or something. I don't know why he left and if I asked him he'd probably have no clue. And, it was very...he would just do weird things that wouldn't make any sense. And I could tell he was frustrated and angry, but I always wondered at the moment if he was frustrated with himself too. I'll never know.

WL: Yeah, very well could be. And you know, with brain injuries as well, things that people do aren't normally the things people would do without a brain injury. But, it doesn't matter...that was your dad. That was my dad. And they do stuff and you're like, why are you doing this? And

so you don't know how much blame to put on the injury or on them. Because, you are conscious and you are making decisions, you know? That was always a struggle.

Paul: Yeah, because I never knew what he was doing was falling under what because I mean, and I guess I'd say I was the most...if I wasn't in the argument or whatever, I was the most sympathetic...empathetic for him because I knew where he was coming from. Him and I think a lot of the same way and I can...I can get down to his level and understand kind of where he's coming from. But I know it's to an extreme and I think I blame the extreme on the injury but the initial decision on him because I can almost picture myself making the same decision but not the same response.

WL: Yeah, that makes sense because you are the closest person to him as far as...

Paul: Yeah, I say the same thing as him, sometimes I act like him too.

WL: Yeah, he passed down half his DNA to you, you know? Right? You are a part of him.

Paul: Right, I just know because...I know...I never saw...I felt like he was always angry at me but I felt like both my mom and sister said the same thing. But my mom always noticed...told me...so I knew it was true, but that he truly, heavily put his anger on me. I never knew why. I never why by myself but my mom always told me it was because I was just like him. And he saw his flaws in me and took them out on me because I had those flaws. And whenever...let's say he was already arguing with my sister and my mom and I could see both sides of it, I would usually agree with the other person over my dad but I could always tell where he's coming from. I would always tell him after, I would never say what he was doing was right, but I see where his logic is.

WL: And did your mom always, or sometimes, take up for you in those situations when your dad was kind of digging in on you a bit?

Paul: Yeah, she would. But, that always makes my dad most...it would always make it worse. Even though...because he is very one on one. He doesn't like other people...he would hate to be in court because people talking for him because I think...I'm the same way. I don't think if someone is talking for me, I feel like they're saying something different than I'm saying even though they probably are saying the same thing. But...he is a very one on one and would a lot of times, make it worse.

WL: Okay, and a couple of more here. Would you say you went through a difficult time in that experience?

Paul: Yes.

WL: For all the reasons you kind of talked about already?

Paul: Yes.

WL: Okay. So, if you had to offer advice to an adolescent who is going through the same experience you are going through, what would you say to them?

Paul: I'd say try to understand where they're coming from and don't fully blame them. I think if my mom had it, my dad...I definitely think even if my mom had it, the responses would be the same. The hostile responses. But I don't think...I don't think someone should fully blame the parent even though they had an injury. But, it's still his actions. Basically don't...try to see where they are coming from at least.

WL: So take their perspective. Yeah that was the biggest thing with my dad was trying to see like, okay...yeah he's mad and yes he said this stuff but I always knew, "but that's not my dad." That's the big thing and that was the toughest thing to swallow...

Paul: Yeah, because if it was his normal self, he would just...he'd get down on my level and just talk to me like a normal human. Where if I did and he would just get very hostile and just very like, whatever...I say physical but he would just...if...a lot of it was like if things weren't where they should have been, he would throw things, you know? Not at anybody, but just very...rough with things.

WL: I will say I know it's different for every person. The years afterwards, it was really crazy. Things were going all over the place and he was kind of going out of his mind. And then, they got the medicines right and things just settled down.

Paul: Yeah.

WL: Like, he was awesome. So hopefully, you said things are kind of on the up and up...

Paul: Yeah, I think it will but my dad is the least medical person ever. Like, his...my dad's mom would get like a cold, or just somebody would get like a cold...or like a regular sickness and he would just shut down and say, well that's too medical for me. I think because of that, he doesn't understand the medical terms. He just kind of shuts down and says I don't understand, and kind of freaks out. And he always just goes these pills are stupid, they're just sugar, they're just placebo's...you know, he doesn't want to take them. And he will lie to anyone and says he's taking them when he's not. And I don't think that will ever change...I mean, it could but I don't think it will.

WL: That affects things, not taking your medicines.

Paul: Yeah, it just doesn't work and I think if he viewed medicine differently, I think his and I's relationship would be different. And I think what's worse is, he doesn't remember the effects of not taking it because he can't remember a lot of things. So he doesn't...he's a very cause and effect kind of person and he doesn't remember the effect of not taking it. So in his mind, why would he, you know?

WL: Right, okay. Two more. Anything you would change about your experience?

Paul: Really, the way I am, I would say no because I really try to view everything I have and grow on it, no matter what happened and I think that's just me as a person. I would say if it's in the past, why worry about it? Just take it and grow on it.

WL: Okay. The last one if just wide open. Anything you want to add before we end? Anything we might have skipped over or that you want to go back to?

Paul: Not that I can really think of.

WL: Okay, well I appreciate your time today. Thank you.

Paul: You're welcome.

### **Paul Second Interview**

WL: Okay, so, some follow up questions here and just kind of like what we did last time. Just answer these for me and then I'll format everything on my end once we're done. And some of these, you might have already touched on during the interview but I just want to follow up just real briefly here.

Paul: Okay!

WL: I know we talked about how your dad changed after the surgery and how you kind of struggled with his anger and rage that was directed pretty much at you as like the primary direction of it. Looking back, what was the most difficult part about that for you?

Paul: I think it was the fact that I know he treated me differently over my sister and my mom. I think it was the fact that he would...he would always treat me differently than the other two and he always held me to a higher standard, if that makes sense?

WL: It does. Yeah, and you mentioned like, your mom always told you it was because you guys were so similar and things that set him off sometimes were maybe things he struggled with as well. Something like that?

Paul: Yeah.

WL: Okay, as you look back over the years since the accident, is there anything in life that you can tie back directly to the accident or the injury, of the effect it had on you? So, for instance, your sister got into teaching and kind of relate that back to how she grew up and back to some things there. Is there anything in your life that you can tie back?

Paul: What do you mean by tie back?

WL: Like, if you can imagine a string leading from the surgery or injury of your dad to something in your life now. Like, there was an effect that it caused in your life that caused you to

make a decision now. For me, for instance, I am studying traumatic brain injuries just because my dad went through one. That's kind of like a direct effect of his injury.

Paul: Oh okay!

WL: So is it like that for you?

Paul: Yeah, I mean, I don't think there's really been any big decisions that I've made solely based off of that but I definitely think...I told myself that like...I purposefully will treat my kids differently if that makes sense?

WL: Mm hmm.

Paul: You know, I think it's just something I just realized, that...you know, I went through that. You know? I don't want my own kids to be treated that way.

WL: Yeah, yeah...that's a big one. Because, often times, you treat your kids as you were treated. So, if you were loved, you treat them as loved. If you had a rough life, they might be a little bit rougher. But, a lot of times, if you had a rough childhood, you treat your kids the opposite because you know how bad it was for you.

Paul: Yeah.

WL: Yeah, that makes sense. Um...the study is focused on the idea of ambiguous loss, meaning you had a loss but it wasn't a permanent loss or a...if your dad would have died, you would have had a sense of closure. But, even though your dad did not die because of the injury or the surgery, do you feel like you experienced a loss of any kind?

Paul: [Long pause]. I'd say to an extent. I would say, you know...I maybe lost a childhood that probably could have gone better. But I try not to sit back on it and think, you know..."man, I really wish it was the other way." You know? Like yeah I lost it, but it's the way it is.

WL: Gotcha, for the childhood. And what about a feeling of loss with your dad? Do you feel like...any loss there?

Paul: Yeah, I would say his and I's connection is different. It's different now than before the incident. Him and I just aren't as close you know? And I have to basically find a way to fill that void. Like when I look around, like trying to build my car...I would kill to have another role model...not really a role model, but a basically a dad who wants to do something with their kid that they're interested in. Because, I went...there were multiple cars that I looked at. I remember looking at a different car and this dad was selling this car because he put all this time and work into it but his son could care less. You know? And I just kind of envied the son because of like, you don't realize the opportunity you had, but he just didn't care. To where...I'd love to just switch places if that makes sense?

WL: It does, absolutely. Okay, and we talked quite a bit about that happened after your dad had his surgery and it came up quite a bit in our conversation. I know the relationship felt hostile, you mentioned that a few times. But, what does that kind of bring up in you? You talked about all that hostility over the years, like how do you process that now?

Paul: Um...I think in my head, I try to play it off, like it wasn't as bad as it used to be...or bad as it was. Because maybe, it gives me some comfort that I won't be that if that makes sense.

WL: Uh huh.

Paul: But I think I downplay it in my head.

WL: Gotcha. Now that you're older, is that still a struggle to be like, "was it as bad as I thought it was" or?

Paul: I think to a small extent.

WL: Okay. So, we also talked about how you viewed yourself before the surgery and afterwards and up to your college years now. Let's place yourself in the middle of your experience. So today, in light of having a brain injured dad who had that major surgery, how would you describe yourself to me, who is interviewing you?

Paul: How it's affected me or how I am?

WL: Um, I guess it could be both. I'm just wondering...one of my research questions is how do adolescents who experience this brain injured parent, how do they describe themselves, like today? Do you view yourself in reference to the brain injury, like it's part of your identity? Do you kind of distance yourself from it?

Paul: I'd say I almost try to distance myself because I know it's brought on hardship in this and that and me distancing myself from it gets me away from it. But I try not to like, forget about it. But, it's not something I want to bring up non-stop.

WL: Gotcha, and when like...meet new people or have relationships with people, does that ever come up as far as you sharing your story or do you keep it in a little more?

Paul: I keep it in a little more, I mean...the people that are really close to me know and they usually end up finding out without me, and I don't mind. I don't, I don't necessarily hide it but I don't tell people, you know? People that know my whole family, they know to an extent what happened.

WL: And with that, keeping it close to the chest and not sharing an awful lot with people right off the bat...as you get older, can you look at your life and say, "okay...this is happening in my life and I wonder if this is from my experience with my dad?" Has that ever happened to you?

Paul: Not really. I wouldn't say.

WL: Ok, a couple of more here and I'll get you going, I know you are at work there. So we talked about you viewed yourself. Part of the question is, how do you view your situation and I think you just answered that. You kind of distance yourself from the injury versus finding your identity in it. You try not to forget what happened but also try not to dwell on it. So that's kind of the situational you, there. And then, today...how would you describe your family today? I know last time, you said things were kind of on the up and up and getting better. But if you were to describe to me, if I said "hey, tell me about your family," how would you describe them right now?

Paul: I'd say we're on the up. It's one of those things where...it's...there's not a constant struggle and I think there ever won't be. It's not constant but I'd say it's...it has to do a lot with my dad just understanding. You know like, my dad wants to understand but his brain just won't let him understand things as quickly. And it's almost like one of those things, like...you're in a group of people and you tell a joke and there's that one guy who doesn't get the joke. And you have to explain the whole joke, and at that point it's not funny anymore. It's one of those things with him, like...you just get tired of repeating the same things. And he'll forget things, so every single time he comes home, he asks the same questions over and over again. And I don't know if he's just trying to make conversation or he really doesn't remember, but there's a lot of just, repeat questions and it gets frustrating, you know?

WL: Would you say...I know you said it's not a constant struggle like these days. Would you say when you were younger and everything happened with the surgery, was it a constant struggle?

Paul: I would say so, because it felt like every day I was trying to avoid him.

WL: Yeah, that can do it man. That's tough because you are trying to avoid everything that is going on with your dad but he's also still your dad so where do you find yourself? Okay, so...the last couple here. How do you think your entire experience, from the injury and surgery to now, how did it shape your self image, you think?

Paul: Um...I think it's hardened me a little bit. I would say, I learn something from it and I grow, I try not to basically make everything terrible. I try to work on it.

WL: Yeah, and do you think it affected your confidence or anything like that?

Paul: Sometimes, sometimes it was hard to deal with. But, I found ways around it.

WL: And what about things like your self-worth or your value? You think that was affected at all through your experience?

Paul: Sometimes.

WL: And do you think it was the experience in particular or was it the emotions your dad experienced, his anger or rage? What do you think it was that affected that a little bit?

Paul: I think it was a collective of all the situations combined, you know? I definitely think his expressive anger really digs deep but it's also a struggle knowing when he's actually trying, that...it's hard because you see him struggle and you keep trying with him. You almost want to just throw your hands up and say, "forget it." You know? But when he is trying, it's a struggle, so it seems like it's a situation where you can never win. Whichever way you go, it just seems like a struggle.

WL: Yeah, and you talked about kind of being caught in the middle in the last conversation, of how you would agree with your mom and sister when an argument happened. And you were like, "I see your point of view." And then later, you'd go tell your dad like, "hey look...I know what you're saying and I understand it, I see how you're feeling." That had to be tough to be in the middle.

Paul: Yeah.

WL: Alright, that is all I have for you. I appreciate it!

Paul: Later!

### **Robert Interview**

WL: How old are you, buddy?

Robert: Uh, just turned 15.

WL: 15? You are going to be driving soon!

Robert: Yeah.

WL: That's exciting! You got a car in mind that you're gonna get? Or that you'd like to get?

Robert: (laughs). Nope!

WL: Just whatever?

Robert: Yeah!

WL: Awesome! Well, buddy, I won't take up much of your time. I know it's summertime and I bet you'd rather be outside playing. So, I'm going to ask you about your dad's head injury. Is that okay?

Robert: Yep.

WL: Okay, awesome. Do you know how old you were when the injury happened to your dad?

Robert: Uh, 13...I'm pretty sure.

WL: 13? So that would be...7th grade? Maybe 6th?

Robert: Yeah.

WL: Awesome, so, do you know what happened to your dad? What caused the brain injury?

Robert: It was a car accident. He got t-boned by a drunk driver.

WL: Oh man, wow. Was he by himself or were other people with him?

Robert: Yeah, he was by himself.

WL: Okay, wow. And then, from that head injury, from what you can remember, do you know how bad it was? Did they say, like, this is a serious injury or?

Robert: Uh, I don't know much about those details. It was really bad, I guess.

WL: Was he in the hospital for a while?

Robert: No, not the hospital, but...[participant trailed off, did not finish the sentence]

WL: Okay. I'm just trying to get a sense of how severe it was. What do you remember about how bad it was? What makes you think that it was bad?

Robert: Uh, just how much changed, in like, a matter of days.

WL: And when you say "changed", what are you talking about there?

Robert: Like, personality and emotions.

WL: Okay, gotcha. So let's go back to that time when the accident happened. Do you remember your first reaction when you heard the news?

Robert: I don't know, because it was 11:30 at night before school and I think I was just watching a movie. And I was like, what? He just got in a car accident?

WL: Yeah.

Robert: That was really it.

WL: Yeah I understand that, especially at night, you know? Let's talk about that night or the next day if you can remember that. What did you feel right after that or when you had the news? Like that night or the next morning, did you have any emotion at all?

Robert: Um, not really. Just like, surprised.

WL: Not really. And what made you surprised?

Robert: I don't know, it's just...there are never really any people out at 11:30 here, so...

WL: Okay, so I'm assuming you guys might live on more like a quiet area, not like a big city?

Robert: Yeah, it's like...not even 100,000 people.

WL: Wow, and the person who t-boned your dad, do you know anything about them?

Robert: They're in jail. Two weeks after the accident, it happened again, so...

WL: Wow, so the same person who hit your dad, they got in another accident two weeks later?

Robert: Yeah.

WL: That's unbelievable. Wow, Okay, so that's kind of like the, general...hey, what happened? kind of questions. So, I am going to go into something different here. I know you said that your dad kind of changed in a matter of days and there were personality and emotional changes...what was your life like before the injury? So, what was your family life like before that?

Robert: Uh, mom was always home and he was always out for work.

WL: Okay.

Robert: And then, whenever he was in town, we'd have like...very exact deadlines for going places. And now we just say, next week we're going to go whenever.

WL: Gotcha, so it sounds like it might have been a little more structured before the accident happened?

Robert: Yeah.

WL: What about your academic life? So let's say, like, before the injury...was anything different about your academics compared to now?

Robert: No, not really. They just...they went from in-life school to online but that we because of Covid.

WL: Gotcha. Did you see or notice any changes in how often your turned in homework or if your grade went from a grade to a different grade?

Robert: Not with the accident, but with online, definitely.

WL: Gotcha, Okay. How about this? Before the accident, tell me about your relationship with your mom and dad in just a few words. My relationship with my mom before the accident was [blank].

Robert: I don't know...I'd say, like, we'd watch like a movie once a week. And dad was like bike rides and stuff. Like, outdoors and indoors with different parents.

WL: Okay, so like, with your mom, you guys would stay inside more and watch a movie once a week. And with your dad, you said that you guys did more outdoor things?

Robert: Yeah, like basketball, biking, sports...

WL: Yeah. Now, where you guys are located, is the weather nice year round or are the winters crazy?

Robert: Winters get a good amount of snow. I say we average around two feet in town. And usually it's like 90's in the summer.

WL: Okay! So not too bad. Awesome. What about before the injury, your relationship with others, Say like, friends or siblings. How were your relationships with other people before the accident?

Robert: Siblings...we never really did much together except like eat together and stuff. Friends didn't really change. Still see most of 'em.

WL: Okay, so you think the friendships with others...that didn't change before or after the accident?

Robert: Not really at all.

WL: Okay. How about this...how about before the injury, how did you view yourself as far as like your self-confidence or something like that.

Robert: I'd say more confident now.

WL: So you think...you say more confident now?

Robert: Yeah.

WL: And why do you think that is?

Robert: I think it's just been like...it's been like two years since the accident and I think I've just gotten older.

WL: Okay.

Robert: Yeah. Mature.

WL: Mature? Yeah, that happens for sure. What about before and after accident, did you have any noticeable changes in your behavior, attitude, or emotions that you can recall?

Robert: Hmm...just more sensitive, but that's it.

WL: When you say sensitive, can you give me an example of that or what you mean by that?

Robert: Like, normal things...some are more [unintelligible] than others.

WL: Some are what?

Robert: More tough than others.

WL: Okay. That sensitivity...Does that include emotional as well?

Robert: Not really.

WL: Okay. And the sensitive thing you just talked about, was that there before the accident happened or just after?

Robert: Uh, not as much.

WL: So present, but not as much. Okay. Do you think, the...accident affected that, like made you a little more sensitive to those sort of things?

Robert: Definitely.

WL: Okay. Perfect, alright. So, let's talk about...your dad first here. Earlier on, you said you noticed some emotional and other changes. Can you give me some details about that? What did you notice specifically on your dad first?

Robert: A lot more relaxed...like, chill about things.

WL: Okay.

Robert: Not much other...just quick personality changes.

WL: So like, personality changes...what exactly did you see?

Robert: Like, what he does on a daily basis.

WL: As far as?

Robert: Of what he likes to do and what he wants, I guess.

WL: Okay, and what about things like emotions as far as your dad's concerned. Was he a certain way before the injury and after he was different? Or?

Robert: Yeah. I don't know how to explain it, but he was. Like temper and stuff. And attention, like...he'd spend two hours on things, now it's like five minutes.

WL: Like temper and stuff. Okay. What about your mom after your dad had his injury. Did you notice anything different about your mom?

Robert: Um, she's much more serious...I don't really know.

WL: What about physical changes in your dad after the injury? Was he able to do the things he was doing before the injury?

Robert: He can't do hard activities with his right side...like he used to play golf and he can't do that.

WL: Got it. Now with his right side, was that the side that he was...injured on?

Robert: No. It was like up in this [points to right side of head] area.

WL: Okay, you talked about how your dad maybe changed a little bit there. You told me that your mom kind of turned a little more serious at that point as well. How did the relationship between family members...you and your dad, you and your mom, you and your siblings...did any of those change after the accident?

Robert: Umm...siblings were closer. Then, the rest was just pretty much the same. I mean, mom went back to work and dad is home.

WL: Okay. And what makes you guys, your siblings...what made you guys closer you think?

Robert: I think there is babysitting more often, like having appointments and stuff.

WL: Okay. With your mom and dad, you said things pretty much stayed the same. Did you have to change anything about how you interacted with your mom or your dad after the injury? Like, you couldn't do things that you could do before? Or was it really all the same?

Robert: Sports wise, not as much. But, the rest was the same.

WL: Okay, now this is a question to think about...it applies just to you. Do you think that the brain injury affected you at all?

Robert: Not really.

WL: Not really, okay. So how did you deal with everything that was happening? I know you said when it happened, you were like...it was late at night and I don't know what to think about that. And then, what about like afterwards? How are you feeling these days with your dad being brain injured?

Robert: It feels like, normal in a way.

WL: Normal meaning it's like it was before the injury?

Robert: I think we just adapted into it and like, it's like more of our everyday life.

WL: And how did you adapt? How did you kind of work into that. Like, life was like this before and then afterwards you were having to adapt a little bit. What did that look like for you guys?

Robert: Like, figuring out what we could do. And, we used to have like basketball and biking...and now it's like a walk.

WL: Okay, so it sounds like you had to adjust your expectations of what was, like, normal, right? Because normal before...you said, was basketball and sports outside.

Robert: Uh huh.

WL: But now, it's like we have to pull that back a little bit. Now it's gonna be a walk?

Robert: Yeah.

WL: With that, how does that make you feel?

Robert: Not really anything...it's just a big change.

WL: How about since the brain injury happened...have you felt more stressed, less stressed, or the same? About school or relationships with others?

Robert: Uh, pretty much the same.

WL: So let's say that something comes along in life, like this brain injury...how do you deal with that? The stress that it might cause? Like, what is your process? So, brain injury happens to your dad...what is your process?

Robert: I don't know. Like, play online with friends more.

WL: Okay. Yeah, kind of almost like a distraction?

Robert: Yeah.

WL: To kind of keep away from that [what's happened with dad].

Robert: Yeah.

WL: Okay. Is that how you deal with most other things? Like, something at school happens or somebody at school says something or relationships get broken off...is that how you handle that stress as well or is it something different?

Robert: It's different but...yeah. I usually just talk about it.

WL: People handle stress a lot of different ways. We talked about when the accident occurred, you didn't really feel any emotions at the time. Would you say that's right?

Robert: Yeah.

WL: What about things like fear or worry or whatever that might be...did you have any of those emotions?

Robert: No.

WL: When the accident happened, or even now, do you have opportunities to discuss what you were feeling with your family? Mom, dad, or siblings?

Robert: Yeah, my mom like every so often.

WL: Okay. Do you talk about it with your siblings at all? Or is it kind of like, how things are?

Robert: We don't really talk about it.

WL: Okay, and what about outside the family. Do you have anybody you can talk to about what's happened or what you are feeling or what's going on?

Robert: Not anymore.

WL: So, before you did? Who did you talk to before?

Robert: My best friend Ben.

WL: Okay! Gotcha! Did you ever talk to anybody at school? Like a counselor or anybody like that?

Robert: Yeah.

WL: How did you think that went?

Robert: We did once a week for a month.

WL: Did you find that useful?

Robert: For a little bit, yeah.

WL: What happened, or changed, after a while?

Robert: It's just like...I don't know. It wasn't surprising anymore.

WL: Gotcha. So like you said earlier, you kind of fell into the routine of what had happened and all that stuff. Okay. You said your performance in school has not changed from before the injury to after the injury?

Robert: Yep.

WL: Okay, perfect. Let's compare real quick...before the injury, how would you describe your life as compared to after the injury?

Robert: Before, a lot more active.

WL: And that's more referring to the sports you talked about earlier?

Robert: Yeah.

WL: And what about after?

Robert: More like chill day trips.

WL: What about your dad before the injury and after the injury. I know we talked about the sports stuff. How about like...you said there were some emotional differences earlier. How would you say your dad was before the injury emotionally? How would you describe that?

Robert: Like, steady. Not rapidly changing like he was after.

WL: Okay, and I want to make sure I get this right. When you say rapidly changing, can you give me an example of that?

Robert: Like, in like 10 minutes, it will go from like happy to angry.

WL: Yeah, what about your mom before and after the injury. I know she was...things have kind of flipped and now she's going to work and things like that. How would you describe any changes in her before and after the injury?

Robert: She's a lot more fiery and fierce now.

WL: In what situations? Is it every day or certain things?

Robert: I don't know...there's like, most things.

WL: What was she like before? So if she is fiery and fierce now, what was she before you think?

Robert: Like, chill and would just make plans and do it.

WL: Okay, I like it. Perfect! Since the injury, do you think your life has improved or gotten worse?

Robert: Improved.

WL: Why do you say improved?

Robert: It's just like a closer family.

WL: Ok, I like it. There are no wrong answers to these. In your opinion, how well do you think you've handled the brain injury with your dad?

Robert: Say, good.

WL: Good, okay. What about on a scale of 1-10, what would you say? With one being the worst and ten being the best?

Robert: Like, 8 or 9.

WL: Okay, and why do you think you've been able to handle it so well?

Robert: I think it's being able to talk to people about unrelated topics.

WL: Got ya, so with people like your friend Ben?

Robert: Uh huh.

WL: Would you say that, your experience you've had with your dad being injured, was a difficult or hard time or how would you describe it if you were telling someone?

Robert: At the start it was harder, but it's pretty easy now.

WL: And then, I think earlier you mentioned it's easier because you are getting used to it more. You think that's the reason?

Robert: Yeah.

WL: Awesome. A couple of more questions and you are good to go. So, let's say I am your age and my parent is going through a traumatic brain injury. What would you say to me? Or what advice do you have to offer?

Robert: Just like, take it slow. Let them stabilize.

WL: You said let them stabilize?

Robert: Yeah.

WL: And what do you mean when you say take it slow?

Robert: Like, slow down...like slow mo, kind of. Instead of going fast like you used to do.

WL: And what part of life do you think that applies to? If my dad is brain injured and you say take it slow, what can I do specifically? Like what's an idea?

Robert: Like, give 'em like 2 or 3 topics, and have them choose 1 one day and another a few days later.

WL: You mean like the injured parent?

Robert: Yeah.

WL: What about this one. Is there anything you would change about your experience? Anything at all?

Robert: No.

WL: Okay, just one more. Is there anything we didn't cover or anything you didn't tell me?

Robert: No.

WL: Alright, Robert...you are good to go!

### **April Interview**

WL: I'm not sure if your mom has told you, but I'm doing some research on traumatic brain injuries, such as what your experience is with having a traumatically brain-injured father. And, I just wanted to ask you some questions if that's okay?

April: Yep.

WL: Awesome. And April, you are 12 years old right?

April: Yeah.

WL: Okay, awesome. Well I'll tell you this right off the bat...I'm writing this huge book about traumatic brain injuries and parents and how you, the kids, deal with it. My dad had a brain

injury as well, when I was in fourth grade, so I wanted to share that with you in that sometimes, people who research things have never experienced them, but I have. And, I kind of understand what you guys might have been going through a little bit, so...if you answer these questions, they'll stay between us. In the report, I won't use your name or anything about you...I'll give you a fake name, and you can be as honest as you want to. Or if you get through this and you're like, no more questions, you can say, "Ray...shhhh!" Okay?

April: [laughs] Okay.

WL: Can I ask how old were you when your dad had his brain injury?

April: Umm...I think I was 11, like, early 11 years or late 10.

WL: Okay, was that fifth grade? Fourth, fifth grade?

April: Yeah.

WL: I used to be a fifth grade teacher, actually so that would have been right around the time I was teaching! Ok, and I talked to your brother about how your dad had his injury. He said it was a car accident?

April: Yeah.

WL: Do you know much about what happened there in the accident?

April: Yeah, do you want me to explain it or?

WL: Yeah, I mean, as much you want to share is fine.

April: Yeah, ok. Well, I remember my dad said that he was coming from a work meeting and then he was at the stoplight thing, I don't know what it's called. And then, he usually looked before he went to be safe, but he didn't that time. Then the car hit him. Ok, I'm bad at explaining this. There was a fast car, I think drunk driver...but I don't know. And then, the car came as my dad was going forward, and hit my dad...my dad's car, on the side of the car. I don't think it was on the side of the car my dad was on, because he hit his head on the seatbelt...like the top of the seatbelt thing. And then, yeah...and then, someone...I don't know what happened when the police or whoever came. I didn't hear much later after it happened.

WL: Okay, and that's okay. And I am sorry to hear that, because I know that can be very frightening to be in a wreck like that. Do you remember, was your dad in the hospital for a while or home the next day or?

April: He was home that night, he just came home I think. My mom went to get him and he came home. He didn't want to deal with having to go the hospital because he was tired and was just driving late at night to get home from the work meeting. Yeah.

WL: Gotcha. And did he eventually go the hospital or doctor?

April: Yeah I think he went to the doctor, yeah.

WL: Okay, and then I guess they told him he had a brain injury at that point?

April: Yeah, I think it was a while before we figured out he had a brain injury.

WL: Do you remember how long that was?

April: No.

WL: Just a while, okay. What about when you first heard the news about the accident or the brain injury, do you remember how you reacted to that? What was your first thought?

April: Um, hmm...I don't really remember.

WL: That's okay. How about when you heard the news, did you have any kind of emotion to that? Like, your heard your dad was in an accident, like what did you think or feel?

April: Well I was just confused, because it was right as I was waking up. I just, didn't even remember that dad was coming home that night. So I was like, wait what? What happened?!

WL: Gotcha, so did you find about it the next morning?

April: Uh, yes!

WL: Okay, so here are some different questions. Those were about the accident, but I want to do some comparing and contrasting. So like, you tell me how things were at one point compared to another point, okay?

April: Uh huh.

WL: So before the head injury, can you tell me what your family life was like, as far as, as a family, we were whatever. How would you describe your family before the accident happened?

April: Um...I guess...hmm...I guess we were pretty normal. We were, well...the work situation was different because our dad was gone most of the time for work and then we had a closer relationship with our mother because we weren't with dad as much, I think. I don't know, because, I was younger back then and don't remember.

WL: Gotcha, and so now I think, your brother had mentioned, your mom is working and your dad might be at home.

April: Uh huh.

WL: Is the same true now, are you closer to your dad now that your mom is at work? Or is it the same?

April: Um, I guess we're just close as a family now.

WL: So closer together. How did you do in school before the injury as far as like, grades?

April: I think I had pretty good grades, average I guess.

WL: Average, okay...not failing any classes?

April: No.

WL: Okay, good! We don't like to see failing classes. Alright. And we talked about your relationship with your family earlier. Do you think you are, as a family, closer now after the injury then before?

April: Yeah.

WL: Okay, why do you think that is?

April: Well, I guess we spend more time as a family. Not just with mom.

WL: Gotcha, so since your dad is home more, you have more time to talk and connect, things like that?

April: Yeah.

WL: Ok, how about, before the injury...how was your relationship with your friends? If I said, hey! How are you with friends, what would you have said?

April: Good, very good.

WL: Good.

April: Some good friends.

WL: Do you have best friends?

April: A lot.

WL: Lots of besties, alright. What about this...before the injury, I was \_\_\_\_\_. How would you describe yourself?

April: I was...uh...hmmm.

WL: I know it's kind of a wide question, like I don't know how I viewed myself. But, like...I just met you today and I didn't know you before the accident, so...how would you describe yourself before the accident?

April: I was more childish I guess, I wasn't as serious about things.

WL: Okay, not as serious. And where do you think the seriousness came from?

April: Probably age. I wouldn't say it has anything to do about the brain injury, actually. Because I actually was younger so that makes sense.

WL: Right, you are getting older, maturing more. Okay! That makes sense. What about...do you remember noticing any changes about how you were feeling before and after the accident? Like your behaviors or emotions. Did you notice anything different before and after?

April: No, not really. Because I don't really remember before the accident.

WL: Gotcha. Because you are getting to the age now where you are cementing some memories into place now and experiencing the world a little differently. You're becoming a teenager which is exciting. That's perfect. Okay!

April: Uh huh!

WL: So, what was life like for you guys right after the accident and injury. Did things change for you all as a family?

April: Yes [dad in the background: "tell him I had a compromised brain injury!"] Participant laughs]. My dad was walking by! Wait, what was the question again?

WL: What was it like right after the brain injury for you or your family. What was that experience like?

April: Oh yeah, it was I don't know...I guess it was kind of more fun because dad wasn't as serious about things.

WL: Okay, you said wasn't as serious? [background noise made it hard to hear the first response].

April: Yeah, we would just go out and have fun some days.

WL: That does sound like fun, awesome. Okay, let me see here. Do you think the brain injury affected you at all?

April: Umm, yeah but like not in a big way I guess.

WL: Okay! What ways do you think it did affect you?

April: Well, hmm...[lots of background noise]. I guess it affected how I ask questions or who I ask questions to in my family. Like, going to friends, I'd probably ask my mom.

WL: Ok, that makes sense. Did you notice anything different about your mom or dad after the accident? Like, oh...this is different than it used to be.

April: Well, I guess conversations would get pretty confusing sometimes, because my dad would probably forget something, and be like what? And then, have to go back and explain it again.

WL: Yeah, that can be a little confusing. What about, Robert was mentioning, he used to play more sports with his dad. What about you? Did you notice anything different about your dad's physical changes...like things he did before the injury versus after...did anything change there?

April: Well, umm...before he could just keep going and could do a lot in a day. Now he needs to take a long break and cool off, I guess.

WL: Yeah. Makes perfect sense, I understand. What about this? Have you ever been stressed in your life before?

April: Uh huh!

WL: Ok, so do you think you are more stressed now or less since the injury.

April: Um, probably more stressed because I am going to middle school and I have new stuff, but with the brain injury, everything is chill. We have to take time to figure everything out, so it's not as stressful.

WL: Okay! Let's see here, how do you cope with stress. Like with the injury, or something at school, or something in your personal life, how do you deal with it?

April: Um, hmm...I guess I take a break and I don't know, take a walk or something.

WL: Okay. Just because, people deal with stress differently.

April: Games too, I play a lot of games. So, yeah.

WL: I do too. I love playing games, they are just a fun way to escape and relax, so...We talked about how you felt when things happened...were you able to express your emotions or talk to somebody? Or how did you get those emotions out into the world?

April: [background noise, dad talking] Wait, what was the question?

WL: Whenever the accident happened, if you felt any emotion, were you able to express them or get them out? Were you able to talk to somebody or confide in a friend, write in a journal, any of those things?

April: Yeah, I guess I wrote down somethings. Write it down.

WL: Okay, and did you ever show any of those writings or were they personal writings?

April: No, personal.

WL: Okay, what about sharing with your family. Did you have the chance to talk to anybody in your family about how you were feeling?

April: Yeah, my mom asked a lot about it.

WL: Gotcha, we're almost done! Just a little but left here, thank you so much for taking the time. So you were, maybe fifth grade at the time...how have you been doing in school since the injury, as far as grades?

April: Probably the same.

WL: Probably the same?

April: The way we grade now is different in middle school than in elementary school so I can't really tell.

WL: Do you feel like it's the same though?

April: Uh huh, I get really good grades.

WL: Gotcha. Since the accident, have you had any issues in school, such as turning in homework or completing your work? Anything like that?

April: Um, I guess I have always had an issue with the time.

WL: Gotcha, so that has stayed the same?

April: Yeah, I guess I've gotten better since there's a lot more in middle school, but yeah.

WL: And also, I know from elementary, you are kind of with a couple of teachers throughout the day and then middle school, you are with a bunch of different teachers.

April: Uh huh.

WL: How about this...looking back since the injury, how would you describe your life now as compared to then? So, before the injury, my life was \_\_\_\_\_. After the injury, my life is \_\_\_\_\_.

April: Before the injury, my life was pretty organized and I knew what would happen each day. I knew what we were doing I guess. And now, we could be doing something random.

WL: Gotcha, and that's like with your family? Like the daily plan?

April: Uh huh.

WL: Do you think that your life has gotten better or worse since the injury?

April: Better I guess.

WL: And why do you think that is?

April: Because I have a better relationship with my family probably.

WL: And why do you think that relationship is better?

April: Hmm, sorry what?

WL: Why do you think that relationship is better?

April: Um, probably because I am more mature now and probably because I can understand what not to say before I say it.

WL: And is that what not to say to your parents or?

April: Like, just rude things. To anyone.

WL: Okay. How well do you think you have handled the injury and the things that have happened to your family? Would you say that you have handled it poorly, good, very good? How would you describe it?

April: I would say very good.

WL: Okay, and if it was on a scale from 1-10 with 1 being terrible and 10 being awesome, where do you think you would be on that scale?

April: Probably an 8.5 or 9.

WL: So, when you went through that injury with your dad, do you think you had a difficult time? Or would you say it's not difficult?

April: Not difficult.

WL: Okay, a couple of more, and you are outta here! Let's say that I'm going through a brain injury with my parent. What advice would you offer me as a kid your age?

April: I guess...umm...problem solving is important, you have to talk to problem solve. You have to talk a lot with your family. You have to go over things. You have to be patient.

WL: All great advice and all real advice, I appreciate that. How about this...is there anything you would change about your experience up to this point and with your dad?

April: Hmm...no, I don't think so.

WL: Ok, and that is really all I have! That was quick and easy and I have a bunch of notes here. Thank you so much for meeting with me, I appreciate it!

April: Thank you.

### **Maggie Interview**

Maggie: Hello!

WL: Hey, how are you?!

Maggie: I'm good.

WL: Good, well hey! I am Ray and I am doing some research on some things for school and wanted to ask you a couple of questions if that's ok?

Maggie: Okay.

WL: Ok, awesome! Maggie, how old are you?

Maggie: 7 years old.

WL: Wow, what grade are you in then?

Maggie: I'm moving into second!

WL: Ooh, that's exciting! What's your favorite subject?

Maggie: Reading!

WL: Ooh that's awesome, I used to be a reading teacher so that is what I like to hear! Okay. What about math or science, you like those?

Maggie: I'm pretty good at math but not really a big fan of science.

WL: Yeah, I am the same way but that's okay. But you like reading though?

Maggie: Uh huh!

WL: Exciting! Awesome! Let me go through here...I'm going to ask you a couple of questions, won't take long. Okay?

Maggie: Uh huh.

WL: And some of the things, I already have gotten from your brother and sister. Let's see...when you heard that your dad had been hurt, what did you think?

Maggie: I thought that it was sad for my dad because he started to show different signs of stuff that he didn't do when he didn't have his brain injury.

WL: Yeah, do you know...can you give me an example of what that was? What did he do that was different?

Maggie: Well he started to fight with my mom more often and a month ago, they...my dad stopped for a while and then this month they started again.

WL: Yeah, and that's ok. I was telling your brother and sister that my dad had a head injury when I was growing up so I've been through there before and understand what you are going through for sure. How are you doing in school? Are you making good grades?

Maggie: Umm, I don't really have grades. It's a little too early in my school for that!

WL: Wow, man! Let's say you do something good for reading or math...what do they do to let you know that you've done a good job?

Maggie: Well, in math...she actually gives us a star if we do good. And, the next day we redo it because our...math is the last thing of our schedule of the day.

WL: Ok, so you get a gold star for when you complete your work or something like that?

Maggie: Well, she just writes one on your paper and...I've actually gotten a star every time I did it.

WL: Gotcha, well that is a great job! I am proud of you, amazing! I am no good at math but I am glad you are at least okay with it! Okay, do you have any friends at school?

Maggie: Yes! I have a couple. I have my friend Griffin and I met him in kindergarten. We stayed at the same school. And my friend Skylar, me and her met like me and Griffin met. And then, I have more friends. One's name is Kallum and it's the same how I met Griffin and Skylar. And...and, all these friends I am talking about. We were all in the same school and we stayed at the same school.

WL: Okay, gotcha. Do you think you have more friends now than before your dad got hurt or about the same?

Maggie: Hmmm...kinda the same but not really cause I can't remember that well.

WL: That's okay! Let me go forward here just a little bit...we talked about how you felt a little bit when your dad was hurt. What about...today, do you still feel that same way? You said you were sad at the time, is it the same or different?

Maggie: Mmm. Different.

WL: Different. What do you think it is now?

Maggie: He's been...acting a lot better than he's been before.

WL: Okay.

Maggie: Like, he started getting more time with us because of all the good treatment he's been getting.

WL: Right, so he's acting better now? So, it's a lot better from when he first got hurt, yeah?

Maggie: Uh huh.

WL: Okay, a couple of more questions for you and you are good to go! Let's see here. So, do you think now...you said you get to spend more time with your dad and things are getting a little bit better. Do you think things are better than they were, let's say, last year?

Maggie: Well, he kind of got his brain injury at the end of last year. But before that at the start of the year, yeah.

WL: So it's gotten better. And then, you seem like you are doing really well. Do you think that everything that is happened with your dad, you're like...I'm good now, I can handle this!

Maggie: Uh huh!

WL: Well good, that's amazing.

Maggie: But I don't really see him that often. Whenever my mom works, my mom's workdays...my sister likes to sleep in a lot so she can't really watch me. And my brother likes to game a lot so he doesn't watch me either. Then my dad is just worrying because there's not really nothing to do so I have two babysitters. One is a little younger than my sister and the other one is just a couple of months younger than my brother.

WL: That's okay! I know things can be a little different, so...what would you want to tell me about your dad's injury? Is there anything you wanted to tell me that I didn't ask you already?

Maggie: Um, not really.

WL: Ok, like I told your brother and sister, I am going to be writing a big report...a book about, maybe this book here [held up book for size], about how people, like you, went through a brain injury with your mom and dad and kind of tell your story. So, I am going to take what you told me and write up a big report then share that with your mom and go from there. I think that's all the questions I have so I appreciate it!

Maggie: Bye!