

FROM TEST TO TESTIMONY: RESILIENCY AFTER A TBI DIAGNOSIS

By

Quanisha Davis

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Director of Thesis: Dr. Archana V. Hegde

Major Department: Human Development and Family Science

Autoethnography research is a relatively new and innovative means of gathering data on oneself to connect to research and theory while advocating for change within a policy, law, and/or environment. When doing my autoethnographic research, titled “From test to testimony: Resiliency after TBI diagnosis”, I had to use my parents’ as a part of my story to lend insights into the early parts of my story and gain access to my past medical records which included my condition and diagnosis. I present myself as a young, African American adult who has experienced a life- changing car accident in her childhood that resulted in a condition known as traumatic brain injury. Traumatic brain injury (TBI) is a condition where the brain is impacted by some sort of force/ trauma that can result in developmental impairments. In my situation, the car accident led to a TBI diagnosis which left me paralyzed on my right side and unable to function as an average 6-7 year old child. Because of the trauma I experienced, my family and others had to make changes to their lives and rely heavily on God to see them through. The Resiliency Model of Family Stress, Adjustment, and Adaptation describes precisely how my family experienced this crisis (family stress), made changes within their environment (adjustment) and

overcame this problem using different resources in their surroundings (adaptation). Fowler's Spiritual theory, is the second theory that aptly helps me document the spiritual journey I experienced during the event. The aftereffects of TBI still remain with me, however, my unique experience and the opportunity to reflect on this story allows me to draw upon a few implications for the professionals and members of the society at large.

FROM TEST TO TESTIMONY: RESILENCY AFTER A TBI DIAGNOSIS

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By

Quanisha Davis

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Quanisha Davis

APPROVED BY:

DIRECTOR OF THESIS: _____

Archana V. Hegde, PhD

COMMITTEE MEMBER: _____

Natalia Sira, PhD

COMMITTEE MEMBER: _____

Paige Averett, PhD

CHAIR OF THE DEPARTMENT OF HUMAN DEVELOPMENT AND FAMILY SCIENCE:

Sharon Ballard, PhD

DEAN OF THE GRADUATE SCHOOL:

Paul J. Gemperline, PhD

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CHAPTER 1: INTRODUCTION

An autoethnography is a qualitative method that uses the researcher as the source of data. It is a new, reflective, and innovative way of research that uses experiences, memories, and personal insights and connects them to social, cultural, and political meanings and understandings (Reilly, 2013). Autoethnography is more than a biography or a self-reflection; it is more of a reflection of the past and interpretation of how it has transformed a person into who they are today. Custer (2014) describes autoethnography as a method that involves a few key elements: 1) helps the researcher transform their views of the past into useful information for the future; 2) helps the researcher become vulnerable by reflecting on the naked truth that is embedded in past experiences and memories; and 3) it can create and welcome change through subjectivity.

Autoethnographies have centered on many ideas and experiences such as chronic pain (Wilbers, 2015), raising a disabled child (Zibricky, 2014), and even fatherhood (Anonymous, 2015). However, there have been no autoethnographies reporting on the effects of TBI on the person who has been impacted during the early childhood years and subsequently the same person transitioning into adulthood. Traumatic brain injury affects more than one million children per year and children can sustain emotional, physical, cognitive, and adaptive effects from it. Victims of TBI often have long-term needs for assistance in performing their daily life activities and adjusting to change in their environments (Dillahunt-Aspillaga, Agonis-Frain, Hanson, Frain, Sosinski, & Ehlke, 2014). Many studies have utilized quantitative methods to conduct research on this topic from parents, caregivers, teachers, and victims' perspective on TBI. A few studies have used qualitative methods to identify the effects of pediatric TBI on the

victim, the victim's family, and others. In these studies they have used interviews as the primary means of data collection method (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015; Prigatano, & Gray, 2007).

In this study, as a young African American woman, I seek the opportunity to self-reflect on a traumatic event that I experienced as a child as it relates to TBI and outcomes of which have impacted my past and present. In this autoethnography, I will narrate my experiences of being a survivor of pediatric TBI that was caused by a car accident, the impact this incident had on my life and current experiences associated with this trauma, make an attempt to extract and generalize my learning's from this incident to shape and change societal views, with the hope that it can inform policy and practice at the governmental/organizational level and become beneficial for other individuals' who have or might experience similar trauma.

CHAPTER 2: LITERATURE REVIEW

Defining TBI

Pediatric TBI, or traumatic brain injury, is an acquired injury to the brain due to a traumatic event to the child's head. The Centers of Disease Control (CDC) defines an acquired brain injury as being caused by "a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain" (CDC, 2014). Rassovsky, Levi, Agranov, Sela-Kaufman, Sverdlik, & Vakil, (2015) states that traumatic brain injury is the most common cause of brain injury resulting in long-term mental and physical disability. Some causes of TBI include falls, motor vehicle crashes, being struck in the head by a moving object or against a stationary one, and assault. Motor vehicle crashes continue to be the leading mechanism of injury for death and disability in pediatric TBI (Popernack, Gray, & Reuter-Rice, 2015).

Uninformed Society

There are a number of reasons why many people are not informed or aware of a TBI and its effects. Some of these reasons include lack of education and the lack of understanding in parents, which may lead the parents to not properly care for their child. A large portion of the public is confused about the different terminologies used to describe a TBI, what the signs and symptoms are, and what action to take if a TBI occurs (McKinlay, 2014). All of these misunderstandings can contribute to the child developing problems in their adulthood if they are not cared for properly. The lack of understanding of what a TBI is and how one can aid the survivor's recovery process is a common issue that many caregivers struggle with. Pappadis,

Sander, Struchen, Leung, & Smith (2011), reported that some individuals believe that a person with a TBI can still be normal even though they may not know who they are or who they know. Some people also believe that people who are in a coma are still conscious and are aware of what is going on around them. The lack of understanding/ education about TBI and its consequences also has the potential to contribute to emotional distress, since it can lead to self-blame, feelings of helplessness, and low self-esteem when persons with the injury are unable to reach unrealistic goals that they set for themselves, or when they compare themselves to peers without injury (Pappadis et al., 2011). Other than consciousness and being in a coma, those with TBI also face misconceptions that they still have a working memory. However, those with TBI actually may suffer from memory loss and have trouble remembering things in their past or even what they did a week ago depending on the severity of the injury. Additionally, Linden, Braiden, and Miller (2013) reported that among members of the general public, adult survivors of brain injury might be perceived as unproductive, untrustworthy and lacking in pride.

Risks Involved

According to research by Roscingo & Swanson (2015), children who are under age 5 or who are between the ages of 15 and 19 are most likely to be at risk for sustaining a TBI. During this age period, teenagers are more likely to engage in risky behaviors such as texting while driving, drinking and driving, and not wearing helmets on motorcycles and other forms of transportation. TBI is even worse for minorities. Minorities such as Blacks and Hispanics have been shown to have worse employment/productivity outcomes, less social integration, and poorer integration in home activities than whites after experiencing TBI (Pappadis et al., 2011). This may be due to a number of factors such as low SES, lower educational attainment, and other related factors. Children with TBI are also at risk for adverse neurobehavioral outcomes.

Outcomes are based primarily on the location of the brain injury and the extent of the injury. Children who are exposed to major damage that has exceeded a long period of time will have harsher outcomes and more difficulties in everyday life. The location of the injury in the brain is also what determines the intervention and resources needed to help recover. Popernack, Gray, and Reuter- Rice (2015) reported that the frontal lobe of the brain is important for executive functioning. Executive functioning involves skills that are needed to achieve goal-directed behaviors, such as attentional control and a working memory for appropriate planning, problem solving, and processing information. These skills are what a child needs to develop in order to have functional independence. (Lax Pericall & Taylor, 2013). These neurobehavioral outcomes can include deficits in cognitive, academic, behavioral, and social outcomes.

Effects of Pediatric TBI

Children with mild to severe TBI are frequently reported to exhibit post- concussive symptoms such as impaired concentration, memory problems, slow information processing, irritability, headaches, dizziness, blurred vision, anxiety, depression, sleep disturbance, fatigue, and noise and light sensitivity (Ganesalingham, Yeates, Ginn, Taylor, Dietrich, Nuss, & Wright, 2008). TBI can affect children's development, socialization, and progression towards independence (Roscingo & Swanson, 2011). Almost 60% of children with TBI develop psychiatric disorders after injury. Greater levels of TBI severity are most likely associated with higher rates of novel psychiatric diagnoses, including externalizing behavior disorders such as attention- deficit hyperactivity disorder and oppositional defiant disorder (Raj, Wade, Cassidy, Taylor, Stancin, Brown & Kirkwood, 2014; Lax Pericall & Taylor, 2013). Other short term effects of TBI include depression, aggression, social isolation, and heightened dependence on caregivers (Dillahunt- Aspillaga et al., 2014). As far as behavioral problems, difficulties in

generalization, inappropriate behavior, stimulus-bound behavior, and recurrent loss of control and unrestrained anger have been reported. Various emotional problems have been observed such as decreased apathy and extreme emotional reactions (Rassovsky et al, 2015). If the child is diagnosed with a TBI early in their childhood, certain consequences may show as they get older. “There is a considerable evidence that pediatric TBI contributes to a range of cognitive and behavioral impairments that are commonly identified as risk factors for antisocial behavior and criminality” (Ryan, Hughes, Godfrey, Rosema, Catroppa, & Anderson, 2015, p. 75). Childhood TBI can possibly cause death, improper functioning, and great stress on the child and the family (Potter, Wade, Walz, Cassedy, Stevens, Yeates, & Taylor, 2011; Stancin, Wade, Walz, Yeates, & Taylor, 2008).

In a qualitative study done by Prigatano & Gray (2007), parents reported having greater concerns about their child having problems developing social relationships. Parents were also concerned about their children’s emotional health because children with TBI, moderate or severe, showed more emotional outbursts and difficulties. Some common emotions, as stated above, are anger and apathy. Other concerns were based on the parent’s emotional support and understanding of the child’s diagnosis. Parents felt that there was little to no support concerning their child’s behavioral problems and psychological problems after being diagnosed with a pediatric TBI in a recent qualitative study (Kirk et al., 2015).

It is important for those who work with the child in the recovery process to be patient, understanding, and compassionate with the child as well as the family. It is even more important for the family to receive frequent checkups over time because the child may still suffer long-term effects of the childhood TBI and the family may not have the proper resources to help the child grow into a well- rounded adult. Even though long- term effects can be physical, some

researchers suggest that long- term effects can be emotional too. Children can have a hard time adjusting to how others define them and limit their possibilities for a meaningful life (Roscingo, Swanson, Vavilala, & Solchany, 2011). If there is a lack of resilience and a support system for the children when they are diagnosed with a TBI, they will more than likely suffer from the long-term effects.

In the next part of the paper I choose theoretical framework that aids my process of thinking and interpretation of my own experience as a TBI survivor. I explain in detail the different frameworks.

Theoretical framework

When a child has been diagnosed with a TBI, their parents, caregivers, and families all have to find the ability to increase their resources to cope efficiently. The child may be somewhat aware of their behavior changes but they cannot understand what they have been diagnosed with and the future consequences. The family must take over the real responsibility of making sure that the child gets the help that they need to become a responsible adult. Hall, Neely-Barnes, Graff, Kreck, Roberts, & Hankins (2012) reported that parents who have children with a disability are more stressed than parents who have children with no disabilities. There are many theories based on resilience and trauma but the family is the main component of the child's ability to be successful despite their diagnosis. Hence the Resiliency Model of Family Stress, Adjustment, and Adaptation is the right lens through which we can interpret the struggles, challenges and triumphs of these families who are faced with such difficult situations.

The Resiliency Model of Family Stress, Adjustment, and Adaptation describes how families in crisis cope and adapt to normative and non- normative stressors using internal and

external resources (Dillahun- Aspillaga, Agonis- Frain, Hanson, Frain, Sosinski, & Ehlke, 2014). According to Hall et al. (2012), The Resiliency Model of Family Stress and Adjustment is a conceptual framework to explore and examine how parents experience a mixture of both stress and benefits to having a child with a disability. This model/ theory is focused on a combination of ecological and developmental perspectives which focuses less on deficiency in families but more so on competency. In other words, it is important to see the family's strengths rather than their weaknesses. Some parents who have children with a disability report enhanced personal and spiritual growth, sense of purpose, and improved relationships and social networks (Hall et al., 2012).

Dillahun- Aspillaga & colleagues (2014) report that the resiliency model includes the family adjustment phase, the family crisis phase, and the family adaptation phase. The family adjustment phase describes the phase where the family defines the stressors and react to them in a positive/ moderate way or a negative way. Hall & colleagues (2012) describes the same process as the family's vulnerability. If the family perceives the stressor as something that can be handled effectively, they are more likely to be resilient. If the family perceives the stressor as something that is too hard or difficult, they will have a harder time coping effectively. When the family perceives the stressor as being too much to handle, they will most likely view the stressor as something they cannot come out of and go into crisis. The family crisis phase includes family disorganization, disruptiveness, and inability to restore stability. This is the stage where families' perspective of the illness becomes apparent. The family recognizes the severity of the disability, the related hardships, and if they have the resources to cope effectively (Hall et al., 2012). The family needs to recognize their resources and use them to the best of their ability to get to the

family adaptation phase. The family adaptation phase describes the resiliency and adaptation that families in crisis use to overcome their trouble.

One component of family adaptation is the family demands. Family demands include initial stressors, prior stressors and how they adapt to them, situational demands, and old established patterns of coping. Another component of family adaptation are the family resources. Resources can be financial, spiritual, and social support. Family appraisals are also an important component of family adaptation. How a family perceives the stressor reflects how well they will adjust (Spina, Zivani, & Nixon, 2005).

As stated earlier, spiritual resources can help the family and the individual with the TBI get through their trauma. Spirituality and resilience are two common concepts that people who experience some kind of trauma often have/ use to cope with their troubles. Farley (2007) defines spirituality as a unique and subjective experience of God. The practice of religious rituals such as worshipping with family, friends, and even strangers can be a form of spirituality. Worshipping with others helps people to find the meaning to life and obtain moral conduct. Moral conduct is what will, in a spiritual view, get someone to heaven. Through their spirituality, people find the faith to get through their trauma and learn to be resilient. Resilience is defined as one's ability to bounce back and one's way of using their strengths to cope with whatever trauma they may be faced with.

Marsh, Brown, & Ebrary (2012) states that spirituality can be defined as the search for meaning, purpose, and connection with self, others, the universe and ultimate reality. Many people confuse this with religion because religion shares many of the same characteristics as spirituality such as giving praise to a particular thing/ person/ idea. Religion is the use of group gatherings to get closer to what the individual wants to worship. Neuman (2011) reports that

there is also growing empirical research showing that a person's religious and spiritual beliefs play a part not only in helping one cope with and recover from illness but also in preventing mental and physical illnesses. A TBI diagnosis can lead children to use spirituality and religion not only to cope with physical illness, but also to try to understand and cope with other difficult situations including physical and emotional abuse. According to Marsh, Brown, & Ebrary (2012), James Fowler's (1981) faith development model which is built on the works of Piaget, Erickson, and Kohlberg, informs most of the current research on children's spiritual development.

Fowler's theory includes 4 stages associated with children: Undifferentiated Faith, the mythic/ literal stage, the synthetic/ conventional stage, and the individual- reflective stage. Undifferentiated faith is described as the period from infancy until about age 2 where the child develops trust due to their environment and their caregiver's behaviors. Trust is a typical component of faith. The mythic/ literal stage, sometimes called the intuitive- projective stage, describes a stage where the child's thinking is fantasy-filled and fluid; it is influenced by imagination and uninfluenced by logic. The synthetic/ conventional stage refers to a period where the child develops concrete operational thinking so they can understand cause and effect and narrate stories (Parker, 2009). This stage is typical in elementary school children who view God as a "parent" that will give them good things when they are good and punish them when they are bad. The individual/ reflective stage is where children can reflect on their belief system as a system and separate the symbols from their meanings (Neuman, 2011).

In conclusion, I have defined the various frameworks I will be using in my study to interpret my life incident. In the following methods section I will explain in detail how autoethnographies are formulated, what are the measures of reliability and validity in a study

like this, who are the informants and specifically what methods were chosen to construct this unique autoethnography.

CHAPTER 3: METHODS

According to Ellis (2004), autoethnography is when someone writes about their personal experiences and identifies the relationship these experiences have to culture. Autoethnographies can display concrete action, dialogue, emotion, spirituality, and self-consciousness. Berry & Patti (2015) state that the idea of autoethnography is to explore the insights/ lessons of memories and connect them to the readers. The readers should read with and read themselves in the story presented by the researcher. The reader should feel as if they were there with the researcher during the times described in their story. Autoethnographic storytelling often comes from and causes moments of personal change and insight. If the researcher puts their heart into their story, or tells the reader exactly how they were feeling and describes the events that took place in great detail, the researcher should discover characteristics within themselves that helped shape who they are today. Hence, in this particular autoethnography I choose to concentrate on two important parts of my story, what happened throughout my car accident and how it has impacted my present life.

Autoethnographic storytelling should have the key concepts of a story. A story has people who represent characters, a crisis that provides dramatic tension, a resolution/ explanation to the crisis, an order of events, and a theme/ lesson (Ellis, 2004). Hence recalling the events surrounding my car accident, what happened during the accident, and what happened after the

accident will be an important part of my story. I will also weave within my story how I viewed my life during and after the course of the accident and compare it with my present life as an adult.

Butz & Besio (2009) state that an autoethnography is not just a confessional tale where the researcher just tells what it is that they know or what they have gone through. Rather an autoethnography should connect to the outside culture and give insight into the bigger picture of changing something and/ or expanding knowledge about a particular phenomenon. Although autoethnographies are primarily research based on self, they may include other people to help describe/ explain a recalled event. Hence, I asked my parents (mother, father, and stepfather) questions during the course of this study to lend more insights into the event surrounding my accident and to know what ensued after that. According to Ellis (2004), family members' perspectives can be included into your own story without the need for any official consent provided they readily agree to participate in your research. In this study my parents helped me expand on my own story by providing additional information. For example, I could ask my parents in detail everything that happened during the accident and thereafter, and additionally obtain from them my own medical records that explained the severity of my injury, exact dates of particular events surrounding the accident and the medical care I received along with direct details about the different types of therapy I went through.

Another parameter of autoethnography is confidentiality. Researchers are asked to stay as confidential as possible if their autoethnographies include other people and events associated with them (Ellis, Adams & Bochner, 2010). Hence, as I write my story, I will not use names of the different people surrounding my TBI incident.

Unlike many other research methods, an autoethnography does not use certain tools to gather data. Tools such as consent forms and IRB approval to work with other individuals/ animals are not necessarily needed because the autoethnography is based on your life story. Autoethnography is a self-referential form of qualitative analysis where a researcher becomes involved in a particular social context and reports his or her subjective experiences and self-transformations. The primary data of autoethnographers are autobiographical first-person self-reflections. Unlike ethnography and quantitative data that may involve a researcher observing as a disguised individual or as a researcher, autoethnography is based on the researcher being their own observer (Corti, Reddy, Choi, & Gillespie, 2015). Autoethnography is a case study approach that is informed by personal observation, experience and reflection, and social theory and research; therefore, it is still valid research but it has different methods involved from the typical researcher- participant form of research (Cook, 2014).

Thus, as an autoethnographic researcher, I used all the aforementioned requirements to narrate the story of my life, highlighting a few significant events, and asking my parents for clarification surrounding the events of my diagnosis. Additionally, in my results section I will skillfully weave the theoretical models and research I have read on this subject to help interpret my incident my life experiences/incidents.

CHAPTER 4: RESULTS

I was a typical female child who loved playing with dolls and hanging out with my friends on the playground. I was taught to pray to God and was made to go to church every Sunday. I knew that God was something/ someone I could not see but as far as I was concerned, if my mommy believed in him then I should too. I knew that he rewarded those who were good and punished those who were bad sort of like a parent. Because of this I made good grades in school and listened to my parents most of the time. As a young child, I depended on my parents to clarify information I did not understand and to make me feel better when things felt rough. Nothing or no one prepared my family nor I for what happened one day in June of 1998.

In the beginning of June 1998, my mother, her former best friend, her two kids, my cousin, and I all loaded into a 1993 Ford Probe to take a trip to Washington D.C. At the time, I referred to my mom's best friend's children as my god siblings and my mom's best friend as my god mother. My mother and my god mother decided that they wanted to take us for a summer vacation trip so we stayed with my god mother's parents to avoid hotel costs. On June 15, 1998, we went around the downtown area of Washington D.C to visit the Lincoln Memorial and all the museums surrounding it. I remember being afraid of Lincoln sitting on that big chair (what a typical 6 ½ year old at the time would think) and my older cousin telling me that he could not hurt me because he was dead. After touring and walking around for a long time, we all decided to get something to eat from one of those hot dog stands (more like a cart). We all got a hotdog,

chips, and a drink and sat on a bench in what looked like a park. My god brother and I were very close prior to this vacation so we played together after we ate. "I had fun at the museums today," I said while he responded with a simple "Me too!"

After a few hours, we all headed back towards my god mother's parent's house. We had to make a pit stop to the gas station and to the grocery store to get ingredients for spaghetti. Spaghetti has always been my favorite food so I believe I was the one who asked for it the most out of all the children. At the grocery store, each child was allowed to get one snack. My god brother got gum while the rest of us grabbed some chips and candy. After leaving the grocery store, we finally headed towards my god mother's parent's house. According to my records, we were heading northbound on Route 1 in Beltsville, Maryland. My god mother was driving and as we approached an intersection, she didn't see oncoming traffic in the median area so she headed out. She attempted to make a left turn onto westbound Lincoln Avenue when an olive green Ford Explorer hit us on the passenger side between 6-6:45 pm. As stated before, my god mother was the driver, my mother was on the passenger side, and all 4 kids (including me) were in the back seat. The Ford Probe we were in turned 360 degrees twice in the middle of the road and after the spinning stopped, my mother was the first to look back.

The scene my mother described to me after she turned around was somewhat unbearable. My mother told me that my god mother was screaming hysterically, my cousin and my god sister were crying, my god brother (age 5) had blood coming out of his ears and nose, and I seemed to be okay. My mother got out of the car first and she said that she saw a white shadow past her eyes. Until this day, she believes that that was our guardian angel. Onlookers all jumped out of their cars to give us blankets and offer emotional support until the ambulances got there. My mother and god mother had to ride in separate ambulances as well as all the children. My mother

and god mother went to the adult hospital while my god brother and I were taken to the Children's National Medical Center. At the adult hospital, my mother and god- mother tried to call to see if we were okay but received no answer so the medical professionals had to call our families in Elizabeth City, North Carolina to report what had happened. Hours went by before our parents knew what was going on with us. A little shuttle carried them to the Children's Hospital while my god sister and my cousin went to my god mother's parents' house. According to doctors that talked to my mom after her release from the hospital, I went into shock and went into a coma after getting off of the ambulance.

Picture a big room divided into about 3 cubicles separated by curtains. When my mother and my god mother walked in, my god brother was the first cubicle that they saw. Blood covered his respirator and blood was all over his face. Another child separated us so my mother had to walk past their cubicle before seeing me. I was on a respirator, a feeding tube, and an IV at 6 ½ years old. According to brain activity levels, my god brother had very little activity while I had a little more. The doctors did not really say much until the next day. On June 16, 1998, my family arrived at the hospital which included my father, my other god mother (and her boyfriend), my maternal grandparents, and my aunt.

In the waiting room, all of my family heard one of the loudest screams they had ever heard. All they heard was "NOOOOOOOO!!!! This can't be true! That's a lie! NOOOO!!!!!" They later determined that the scream was from my god mother because my god brother had just died (at the age of 5). A few tears were shed before one doctor had to come and talk to my parents about what was going on with me. The doctor reported that I had a traumatic brain injury. My mother and father both looked at each other before looking at the doctor and responding with "What is that?" The doctor informed them that traumatic brain injury is a

condition that can occur when the brain experiences some sort of severe trauma that could result in disability and complications later in life.

He went on to tell them that the next few hours would be critical and that I could possibly make a full recovery or could suffer greater consequences. My parents were told that I may not be able to walk, talk properly, and/ or have learning disabilities. I could not have another blow to the head or I would die/ have major consequences. The doctor also told them that I could possibly need care and resources such as special education if my brain did not find other ways to do regular things. My parents were told that I had lost a part of my brain but I did not lose enough to do brain surgery. Because I was still young, I had a higher chance of resilience so my brain would make up for what it was missing but I would still suffer with memory problems. A CAT scan done the next day, June 17, 1998, reported that I had a small subarachnoid hemorrhage and a grade 1-2 liver laceration. I had injuries in the left frontal lobe of my brain as well as the high right parietal lobe. The best way I can explain all of this is that I had bleeding on my brain that resulted in my inability to walk, talk, and function properly and damage to my liver that healed mostly on its own. While still in a coma, doctors reported that my right side was paralyzed.

I stayed in the coma for a total of 15 days and on the fifth day, I started to make a little progress. A nurse told my father that it was very important for him to keep talking to me and whisper in my ear everyday while holding my hand. My father told me that he would tell me he loved me and that everything would be okay. One day, I started to squeeze his hand back when he talked to me. After opening my eyes within the next few days, I only wanted my mother and father. I was scared of everyone else, I was constantly screaming whenever doctors or other people came to visit and I would wake up during the night screaming and fall back asleep. One

particular story my father told me was that I had to be carried to the bathroom because I was scared to touch the floor. Because I still did not have proper functioning in my right side, I had to start back wearing diapers. I was using one word sentences such as “mama” and “dada.” I also had to be handfed once the feeding tubes were removed.

My hometown, Elizabeth City, started a prayer line on our local radio station for me. My parents sung to me and played gospel songs such as “Shake the devil off” and “Jesus will pick you up” by Dorothy Norwood. On my 7th birthday, June 19, 1998, the medical staff gave me a birthday party with balloons and a cake. My father told me that I just smiled and looked at everyone. Family and friends came to visit me in Washington D.C. One particular story was when one of my cousins brought me a doll baby that I named Jingles. She was a brown water baby with big black eyes, perky lips, and a small body (my cousin had lost her water pump). I still have her with me until this day.

After my care at the Children’s Hospital in Washington D.C, I was sent to the Charlotte Rehabilitation Center of North Carolina. My mother, a single parent at the time, had to apply for Medicaid due to hospital costs and was advised to take a leave of absence from her job for 4-6 months. The representatives of Medicaid told her that I would have to be sent to a rehab in North Carolina in order for them to help. My mother wanted me to go to Greenville’s pediatric unit but it was already full which is why I had to be sent to Charlotte. The Children’s Hospital’s EMT carried me on a bed into the truck. My mother was with me while my father had to follow behind in his car. My mother told me she loved me and how everything was going to be okay during the whole ride. I did not respond to her voice or show any signs of awareness. After riding for about 3 hours or more, we hit a bump in the road. I rose up from the hospital bed and said “Wait, Wait.” My mother looked behind the ambulance and did not see my father.

Soon after my mother realized I wanted the driver of the ambulance to wait for my father, we arrived at Charlotte's Rehabilitation Center on July 1, 1998. After waiting at the front, medical staff asked a few questions and switched me to a bed with a zipper to it. Because I was coming out of a coma, I could be a danger to myself and others if left on a regular bed. My mom shed a few tears because I was crying. I did not like that bed and I still remember it until this day. On July 2, 1998, the medical staff came to talk with my parents and me about the kind of therapy I would be receiving. I looked at my father and then looked at the staff and I said "If you hurt me, my daddy will hurt you." For my stay there, I received speech therapy, occupational therapy, and physical therapy (all of which were more intense than Washington D.C) for approximately 2-3 hours a day. I had to be active with play equipment, improve memory with memory card games and recall of events in a story or what I did the previous day, and other similar activities. My parents were not allowed to participate in any of this; instead, they had to go out and about in Charlotte and let the professionals do their jobs. One parent had to stay away at the Hospitality House (similar to the Ronald McDonald House) while the other came to visit me. I felt very lonely at times, especially at night with the zipped up bed, but I got very close to one nurse in particular. She brought me banana nut bread a few times and came to sit with me whenever she had free time. I also had Jingles there with me to hold at night when I had to say goodbye to my parents. Midway through my stay there, my parents were allowed to come watch me during therapy and see my progress. After some of my memory came back, I started to ask questions about my god brother. My parents had to inform me that he had died and I ended up crying.

The estimated time of stay was about 4-6 months due to the complications I suffered in the accident. Because my progress was so outstanding, I was released from Charlotte Rehabilitation Center on July 15, 1998 testing above grade level in academics. When arriving at

my maternal grandmother's house, my maternal grandfather was pacing up and down the driveway and yelled to everyone inside the house "They're here, my babies are finally home!" My cousin (the one in the accident with me) was the first to run and hug me when I got out of the car. When I went inside, there was a line- up of food such as fried chicken, turkey wings, collard greens, rolls, sweet potato pie, and sweet tea. My grandmother told me that she did not allow anyone to touch anything until I came home but two of my cousins were hard- headed and snuck some pieces of chicken behind her back. Everyone in the house greeted me, hugged me, cried, and thanked God that I was okay after I finished smelling all the food. I remember seeing my great aunt, who was blind, smiling when she heard my voice.

Changes had to be made in my environment after returning to school. In my case, my mother had to meet with my elementary school's principal and request the teacher she wanted me to have and discuss the changes that needed to happen with the school itself because of my traumatic brain injury. Central Elementary School, of Elizabeth City, North Carolina, was one of the first schools in Pasquotank County that had to change the cases that held the fire extinguishers. The case (before my diagnosis) was pointy at the ends but the new case was made to be more rounded to avoid the possibility of me hurting myself. Even though I was not put into special education classes, my mother met with a special education director to discuss TBI, its effects, what to expect, and what should be done to help me advance in school. The director came to check on me randomly over my school career to see if I was progressing efficiently. The director suggested that I be put on the 504 plan that would allow me more time on assignments and rest when I started to get a headache. I was not put on this plan until I went to middle school. When I asked my mother why she waited to put me on it, she stated that because she was a teacher at Central Elementary school and knew the staff personally, she did not feel the need to

start a plan that was already happening. In other words, because my teachers were so caring and patient, I had no need for the plan until I got into unfamiliar territory.

Other than making sure I was academically progressing, my parents had to take me to my pediatrician in Elizabeth City whenever I had extreme headaches. They also had to take me back to Charlotte Rehab every year for CAT scans to make sure my brain was still doing okay. My mother told me that she became more aware of my behaviors after that because doctors told her to monitor me closely. She had to take me out of gymnastics and I was not allowed to participate in any contact activity or sport. When I went out on the playground, I had to stick to playing in the sand and playing on easily accessible equipment. I had to give up my trampoline that I was given on Christmas one year because my parents were afraid that I would try to do flips like my cousin would do. When asked how they made it through these changes they had to make for me and what they think helped me to get to the place I am now, my parents report that it was nobody or nothing but God. Their faith in God, prayer, and close relatives/ friends is what helped them get through those hard times and what helped me be as successful as I am today. My parents had to rely on family, friends, and my pediatrician to keep them informed and encouraged about my TBI because there were not local programs or services for TBI survivors during that time.

One year, in middle school, I came home with my progress report. My mom had met my stepfather prior to this so he was there with my mom when I showed them my report. I had all A's and B's except for one class. I was sitting on our white deep freezer in my mom's bedroom when I started to cry. The grade I looked at was a C and it was a C by two points. My mother and stepfather had to calm me down and tell me that a C was not bad and that I should be proud of myself. I even called my father and told him (while crying) and he tried to calm me down. All of my parents tell me that ever since the accident, I put more pressure on myself (especially in

academics) to be perfect. Until this day, I still try to be perfect with my grades and academic success. Would you believe me if I told you that I am in graduate school at a university now? Sometimes, I have a hard time believing it myself. Ever since that time in middle school, I have always had an A-B average in school (maybe 1 or 2 C's in Spanish and Chemistry) and I graduated high school and college with honors. I could not tell you how I made it through these years with somewhat of a memory problem. The only answer I can give is God.

My faith has led me to reflect many times on this car accident and the effects I suffered and I have come to the conclusion that God is real not just because my mother said so (in my elementary days) but because I have experienced a life changing miracle. Medicine, science, and any other earthly concept cannot explain how I was able to turn my test into my testimony. Sure, doctors told my parents that I could make a full recovery and my brain would make up for what it lost but science cannot explain how I am able to study and push myself beyond measures to reach my highest potential. By all means, I am blessed! This road has not been easy by any means but with God, family, friends, and school, I have and will get past obstacles. My story based on my near death experience in a car accident helped me see that there is a God and he is the reason I have been academically successful and able to cope with life ever since the accident.

Academic success is important, do not get me wrong, but emotional and mental health is something that other people do not understand when it comes to TBI. When I was showing academic progress throughout school, all the medical professionals disappeared. Other than problems with my memory, my parents were not told of the emotional and mental issues I may suffer. I do not like that I cannot remember events prior to the accident such as my trip with my dad and family to Kings Dominion or watching Barney with my dad when he got home from work. But even worse than that, I overthink everything! Yes, I am a woman so we have this

stereotype that we overthink anyway but it is even worse than the stereotype. Imagine your brain having a on and off switch to it so when you are up and about, the switch is on and when you take a shower and lay on your bed/ couch, the switch goes off. My switch never turns off! I am not saying that I never sleep but I am saying it is harder than anything just to get me to relax. I am always thinking about school, work, family, boyfriends, or even random things that keep me up at night and do not allow me to rest completely. If you ask any of my classmates, they will probably tell you that I am always one of the first to complete an assignment. It is not that I want bragging rights or something but that is how I am able to function in school.

I suffer from depressive symptoms also. I have not been diagnosed with depression because I have not made it to a psychologist/ psychiatrist yet. I do not know if I am ashamed to go to one or that I try to find other ways to cope. My primary physician prescribes me antidepressants to help with my mood swings and feelings of anxiety and sadness but sometimes that does not feel like it is enough. Sometimes, I feel guilty that I take them because God has brought me out of so many things so I feel that I need to depend on him more to get me out of this funk I have been in lately. I do not take the antidepressants currently due to this reason and some side effects I was suffering but my prescription still has refills left. I will not say that I will never take them again and that I have found efficient ways of coping just yet but I am progressing. I try to stay involved in school and work and be around positive people. I try to go to church a lot more and pray every night. Praying to God has been my main way of dealing with struggles in my life but I feel that getting to the root of what I view as a problem will help build myself up even more. It is not easy to explain to others what is going on in your mind and why you overthink everything. It is not easy trying to find ways to adjust to problems that some people would not even view as problems and it is not easy when you feel that you have given up

on God when you take antidepressants. I think about my god brother sometimes and wonder why he had to die. He was a wonderful person who made everyone smile. I will never understand why God had to take him up to heaven as soon as he did. Within my faith, it is not a good thing to question God but this is something I struggle with sometimes. I am not saying that antidepressants or people who need to take them is bad; I am just trying other ways to deal with these effects and the pain of losing my god brother. Without that experience and other situations I have been through in my life, I would not know God as much as I do now. Even when times get rough and I feel like giving up, I recall my experience in the car accident and push myself to keep going. Not only did the car accident bring about personal change but it changed the people around me. More people in my community started praying, seeking out God, and asking me to give my testimony. I have met others who have shared their experiences with TBI as well which has also impacted me to tell my story.

A couple of months ago, I met a guy who had a TBI also and we became very close. I really liked him and wanted a relationship with him but he had other plans. When he came over my house one day, he saw Jingles laying on my bed. He asked me what I was doing with a doll baby at the age of 23. He referred to me as a big baby and started laughing. I laughed with him while proceeding to tell him about my story and why I carried the little water baby wherever I moved to. I told him that I had a TBI as a result of a car accident and that Jingles was my angel who reminded me that I was a survivor. He looked at me in amazement and told me that he had been in a car accident and that he had suffered brain damage as well. During the time that we spent together, we talked about what it was like to have a TBI and how other people just do not understand what we are dealing with. He was kind of like a therapy for me because he knew

exactly where I was coming from. I became too dependent on him for emotional support because there was no one else around.

I never heard of any support groups for people with my condition before starting this research. My parents and I agree that there needs to be more awareness about TBI and more support groups for survivors and their families, especially in smaller cities. If you turn on your local news or go around a typical child development facility, you will likely see information concerning autism or allergies, but you will rarely see anything about TBI. Thus, in my discussion and implication section I draw upon my experiences to inform how professionals and society can address this important issue.

CHAPTER 5: DISCUSSION AND IMPLICATIONS

Theory

Theory has helped shape this research into what it is because it helped me see the perspectives of my parents as well as connect it to my inner feelings and research. The Resiliency Model of Family Stress, Adjustment, and Adaptation discusses how a crisis can be turned into an opportunity to expand resources and grow closer as a family. The family can help one another turn their “test” into their “testimony” if they decrease their stress and lean on their faith, outside family, or other forms of support. As discussed earlier, Dillahunt- Aspillaga & colleagues (2014) reported that the resiliency model includes the family crisis phase, the family adaptation phase, and the family adjustment phase. For any parent who cares about their child (ren), they would most likely view a car accident as something horrible and would have a hard time adjusting to the stressor/ crisis (car accident) because it is/ was unexpected. My car accident happened during an unexpected time because what was supposed to be a vacation into something detrimental that I will never forget. According to my parents, seeing their child being in a coma and being diagnosed with TBI was one of the most horrible events of their life. This crisis stage that my family went through left them discouraged, angry, and sad so they had to find a way to adjust and adapt to get through my recovery. Having an older child resort back to a “baby phase” led my parents to reach out to God and others to help them get through. My godmother and her daughter felt some of the same emotions my parents felt because they lost someone who was important to them in the car accident. They had to learn to adjust to life without my god brother.

My story tells how my family learned to use their resources such as prayer, professionals, and family bonding to overcome their crisis phase, adapt to my condition, and adjust their lifestyles to care for me properly. Greater stress and loss leads to forming relationships with others and expanding resources so that the family can get to the adaptation stage (Dillahun- Aspillaga et al., 2014). During those days, my family prayed every day for my full recovery. As discussed earlier, some parents who have children with a disability report enhanced personal and spiritual growth, sense of purpose, and improved relationships and social networks when adjusting to a crisis according to the Resiliency Model of Family Stress, Adjustment, and Adaptation (Hall et. al, 2012). The adaptation stage describes the changes the family and the environment the child is around must endure due to the illness (Spina, Zivani, & Nixon, 2005). This includes changing their personal lifestyles and helping others adjust as well. In my case, the changes made in my elementary school and what I was allowed to participate in were a part of the adaptation stage.

This theory and how it connects to my story should motivate parents and professionals to seek out help during stress. It is very important not to let the accident or whatever the crisis may be get the best of them during the crisis phase as discussed in this theory. It is also important to teach parents and families that the child needs attention, love, care, and patience. My parents were there for me every step of the way by following the doctor's orders, talking to me every day, and putting their differences aside to focus primarily on my needs during my coma and recovery. My family learned how to adapt to my diagnosis by praying, asking more questions to gain clarity, and reaching out to outside family/ resources. What worked for my family may not work for everyone because some people may not believe in praying or having other people know what is going on with their child. Therefore, family and professionals should figure out what works best for them and teach them ways to be effective to adapt to their child's diagnosis or the

crisis that they have to endure. Last but not least, adjusting their lifestyles around the crisis has to be done. My parents and family had to surround their work schedules to monitor me closely, make sure that my teachers and others knew how to interact with me, and put limits on what I was allowed to do. For a further example, a child who has been diagnosed with asthma should not have parents or others smoking around them. The parents should go outside and/ or tell others what they are allowed to do when their child is around them.

Fowler's spirituality theory defines the stages humans go through in connection to faith and life experience. This theory includes the phases: Undifferentiated faith, the mythic/ literal stage, the synthetic/ conventional stage, and the individual- reflective stage (Parker, 2009). As a young child who was in a car accident, I had to rely heavily on my family to make sure I had the proper care and pray for my healing because I was unable to. This theory speaks more about my parent's faith and spirituality than my own because they had to find a way to cope and remain strong through everything they went through. As stated earlier, everyone may not pray or believe in spirituality so this theory may have its limits when it comes to them. My parents grew up surrounded by praying parents who believed in God so they taught me the same. During my stay at the hospital and rehab, my parents, other family members, and the people in my hometown prayed for my recovery. They listened to gospel music and even started a prayer line on a local radio station. Other parents and families need to find what helps them cope effectively and build on that.

Implication for Professionals

TBI can effect more than just the survivor and their family, it can effect neighbors, classmates, friends, and even strangers. An estimated 1.7 million people sustain a TBI annually. Out of these 1.7 million people, 52,000 die, 275,000 are hospitalized, and 1.365 million, nearly

80%, are treated and released from an emergency department. Direct medical costs and indirect costs of TBI, such as lost productivity, totaled an estimated \$60 billion in the United States in 2000 (Centers for Disease Control and Prevention, 2016). This should be alarming statistics to professionals because the costs of TBI effects more than just the family! If we all work together in professionalism and society, we can conquer the effects and struggles of the individuals and their families.

According to Schachar and others (2015), medical and mental health professionals need to pay more attention to TBI because of the risk factors and effects that could occur. Mental illnesses are risk factors for TBI. Untreated ADHD seems to add risk for TBI. Counseling about injury prevention ought to be a standard component of care for children and adolescents with psychopathology, particularly ADHD and aggression, as well as those who have already suffered a TBI. Many parents may think that a little fall may not result in detrimental effects such as TBI but education from medical/ mental health professionals is needed to save lives and promote resiliency!

What is the next step to helping victims and their families? Schacher and colleagues (2015) suggest that more research needs to be done to help clearly define the terminology surrounding TBI, the effects that can occur, and what the families need in order to help care for the victim. Secondly, experiments with drug based and non- drug based therapies need to be done to see what can work effectively to decrease aggressive behaviors and other effects suffered from TBI. Because there is an urgent need for evidence based practice guidelines for the full range of mental health consequences of TBI including non-pharmacological interventions aimed at improving cognitive, academic and psychosocial outcomes, more medical/ mental health professionals need to advocate for change in policy and treatment of these individuals suffering

from TBI. The key to success is not just diagnosing the individuals and treating them immediately after the diagnosis; the key is to keep checking up on them and their families over time. If more professionals found a connection with the individual, the family, and research-based practices, people with TBI could succeed in academics, social skills, and life choices even in adulthood.

Murphy & Carmine (2012) suggests that helping the individual help themselves is another component of resiliency after a TBI diagnosis. Whether the individual was diagnosed in their childhood or later in life, they should still be maintaining a healthy body weight for mobility and functional independence. Rehabilitation teams should center on nutrition, weight control, and hydration to help the individuals with TBI. Other suggestions include making sure individuals take their medications as recommended and teach them about the counter effects that other drugs can have. These drugs may include nicotine, caffeine and other substances that could effects the benefits of the treatment prescribed by a medical professional. It is important that individuals with TBI and their families make sure that they seek annual checkups to make sure everything is functioning the way it is supposed to.

Support groups and participation in a religious organization has also been noted as a way to promote the well- being on the individual diagnosed with TBI. Powell, Gilson, and Collin (2012) stated that individuals who had been diagnosed with TBI earlier in life were more successful in life in they had sought out support from local groups and aimed towards a growth in their spirituality. Chaplains and pastors should reach out to people a lot more because even though someone may not be vocal about their struggles with TBI, they may need someone to take the time to pray over them and even counsel them through faith.

Teachers and educators also need to be well aware of TBI and the effects on individuals. Because TBI can impair the functioning of the brain, people who have been diagnosed may suffer from cognitive impairments and emotional problems (Roscingo & Swanson, 2011; Raj, et al., 2014; Lax Perical & Taylor, 2013). Teachers may have trouble teaching these students because they may act out, be aggressive, or have problems with assignments and paying attention. This is why parents, professionals, and teachers need to keep the lines of communication open to promote effective plans such as the 504 plan discussed above. Plans such as these will give the child more time on tests, excused absence from class, and other helpful tools for the child and the teacher.

The burden of adjusting to TBI and the associated residuals is not experienced solely by the child—it is an issue experienced by family, friends, and school personnel. If not addressed properly, it can truly effect the child and their family’s life (Pierson & Noggle, 2010). When thinking about the family system, the child is the center but the parents all share the feelings and effects that the child may suffer. When the family is burdened with stress and medical bills, they may have to miss work or increase work hours which turns into another bill concerning child care. The school must change some of their policies (like the fire extinguisher in my situation) which can result in asking more money from the government. If the child is involved in criminal activity, they will likely be arrested and/ or the parent is forced to pay fines. According to de Kloet, Lambregts, Berger, van Markus, Wolterbeek, & Vliet (2015), consequences of pediatric TBI may have negative effects on parental coping, problem-solving, and communication reflected by increased rates of family disruption, divorce, and dysfunctioning of brothers or sisters after a TBI diagnosis. A TBI diagnosis can disrupt the entire family system and cause great stress on the family when trying to adjust. It is important for the families of these survivors

to receive marital counseling and family counseling to maintain the family structure. These families may feel that they are alone or embarrassed to admit that they need help which is the reason that more research needs to reach out to families of TBI survivors. My family used God, friends, and family to keep them encouraged but there are some that may not be as fortunate. This is where child professionals and researchers need to step in and stay with the family post diagnosis

Implications for Society

Doing this research on TBI as well as myself has really opened my eyes and my heart. I am forever grateful to God, my family, and others for their help with this process. As I stated before, some people may not be as fortunate as me to have a supporting family and the resources they need to cope. It is important for society to increase the awareness of TBI and its effects so that no child ever feels that they have to suffer alone or feel like the nice doctors and nurses, that they once had a relationship with, have disappeared on them. Yes, doctors, nurses, and other medical professionals have a lot of patients and work that they have to do but children (age 6 ½ , younger or older) do not understand that. It would have been nice for there to be programs that my parents and I could attend to learn more about what could happen as I got older. My mother is a teacher in North Carolina so she receives insurance which includes mental health and other visits with professionals. It is not free, by any means, but it would cost me a good amount of money each visit with a mental health counselor simply because of the copay. When you have to have money for food, shelter, and clothing, mental health is something that is somewhat put on the backburner until money is not a big issue. I attend a university where I can receive the mental health counseling I need but what happens when I graduate? What about the families who cannot afford insurance? The government should make it even more affordable for victims who have

suffered from this condition to get mental counseling. Some people know that those who have been diagnosed with TBI while they were on duty in the army are provided financial help with medical bills, medication, and counseling. Those who suffer from TBI due to other causes deserve the same type of treatment.

According to Humphreys, Wood, Phillips, and Macey (2013), costs of TBI can vary depending on medical insurance, costs of different treatments/ medications, employment and financial help, and support from the local community, family and/or friends. Studies presented in the article concluded that costs for families can range from \$33,284 to \$35,954 for mild and \$25,174 to \$81,153 a year for moderate TBI. A 2002 study presented in the same article concluded that TBI costs society as a whole \$81 million in direct healthcare costs and \$2.3 billion in indirect healthcare costs (Humphreys et al., 2013). With families who have little to no health insurance, the emotional costs are already a big enough burden. Why should society let the family suffer through financial burdens too? Yes, there are programs such as Medicaid and Medicare that may help with some costs but they may not cover everything which leads the family and the individual to be even more stressed than they already are.

Schachar, Park, & Dennis (2015) states that TBI is the most common cause of death and disability in children. One in thirty children will sustain TBI due to abuse, car accidents, or other trauma experiences on the brain. Something as prevalent as this needs to be paid more attention to. Elbogen, Wolfe, Cueva, Sullivan, & Johnson (2015) states that TBI increases the chances that an individual will engage in criminal activity and violence. If a child with a TBI grows up to participate in criminal activity and violence, they will suffer from consequences such as incarceration, social isolation, and increasing the risk to their surrounding environment. Society needs to pay more attention to this phenomenon to increase the success of individuals with TBI

and decrease the chances that they will fall victim to criminality related to the effects suffered from TBI. Murphy and Carmine (2012) suggests that community supports such as weight loss groups and fitness centers should be considered as part of some individual's stable activity pattern to promote physical and mental health. Providing programs that center on resiliency and positivity are important for those who have been diagnosed with TBI. Providing jobs and services for those who may suffer from memory troubles or physical disabilities due to TBI may not be easy for employers and professionals, but it is needed to help these individuals succeed in life.

Ilie, Mann, Hamilton, Adlaf, Boak, Asbridge, & Cusimano (2015) reports that children who suffer from TBI can be burdened from a range of cognitive dysfunction, substance abuse, anxiety, depression, and suicidality, to poor academic performance and social impairments that contribute to the development of dysfunctional relationships. Survivors of TBI can have a harder time in school and work and suffer great stress from overthinking. They can also suffer from depressive symptoms such as sadness, loss of sleep, and decreased appetites. The stress from all of these symptoms could be the reason why TBI survivors participate in substance abuse. This substance abuse could be a contributor to them participating in criminal activity. Ryan, Anderson, Godfrey, Eren, Rosema, Taylor, & Catroppa, (2013) suggests that TBI survivors suffer from emotional and communication problems also. Difficulty with conversational turn taking, maintaining conversational distance and adjusting language to meet changing social constraints may contribute to poor social adjustment. If these survivors suffer from these communication problems, they may have a harder time maintaining friendships, applying for a job in an interview, and developing good communication in romantic relationships. I have had some trouble in these areas as well. This is why society as a whole needs to become more

educated concerning TBI and promote advocacy and the change in policy after a TBI diagnosis. Although, autoethnography is a powerful means of research, it has its own limitations. These have been addressed in the next section of the paper.

Limitations

Although autoethnography allows for the self-observation of teaching practices, examination of relationships with learners, and reflection on the impact of novel teaching methods to inform one's own understandings and practices in ways that can be shared with others, there are a few limitations (Farrell, Bourgeois-Law, Regehr, & Ajjawi, 2015). Many critics have argued that the exclusive use of the self as a data source results in narcissistic and self-absorptive results. In other words, not using other humans as a means of gathering data can give others the impression that autoethnographic researchers are not reliable and the measures they use to research themselves cannot be repeated by someone else to get the same results. One of the main downfalls of autoethnography is failing to consider that confidentiality must still apply in self-narrative (Farrell et al., 2015). It is important for other readers to get a sense of what it is you want them to understand but it is also important for you, as a researcher, to not give away too much information. As discussed earlier, autoethnography does not require consent forms or IRB approvals to work with human/ animal subjects (Ellis, 2004). Many may question this simply because when research is approved by the IRB, it is more likely to be valid and precise. Autoethnography is based on one's personal experience so the researcher has the responsibility to report the truth about everything they report and develop trust with their readers by letting the readers feel and experience their vulnerability.

Conclusions: Why this research matters

Based on my story, many people in my hometown and surrounding areas did not know exactly what to do or how to interact with me after the diagnosis. TBI is not just an injury to the brain, it is an injury that can affect all parts of the body and even affect one's emotional state. When I was able to return to school after recovery and function properly, my case worker, my doctors, and other professionals who helped me along the way, disappeared. The reason I am using the word "disappeared," is because to a child (as I was after the car accident), any adult that was there for you and went away for any reason, has left you to suffer alone.

Although I had my family, teachers, and classmates there with me, I cannot remember one time that any professional checked up on me after they realized I was successful in academics. What everyone fails to realize is that the emotional state and some physical conditions I face today could be a result of TBI. It is not okay for anyone to be forgotten about just because they "seem" to be fine. In other words, TBI can have lifelong effects and there are times where family and friends are not enough. Doctors, child professionals, and the public in general need to be more aware of TBI so they will know that even when a child is young and shows resiliency to get past the diagnosis, they will still need guidance and compassion as they grow older. The families of these children may not know how to tell their child why they have a harder time adjusting to changes in their lives or why their brains never fully rest due to overthinking. I am not telling you about my situation because I just want to tell it. I am telling my story because I realized that TBI is not a common concern among society. In all my child development classes in my undergraduate career and graduate career, I have not heard anything about TBI. There is an autism certification that I am obtaining now so that I can work with kids with this disability and their families but there is no certification to work with a child with a TBI.

TBI has different forms, causes, and levels of severity just like autism and other developmental disabilities. TBI is a life-long disability that can affect me and others that suffer with it for the rest of our lives. Why is it not just as important as autism or other disabilities? Why is there not a voice for people like me? As discussed in my research, TBI increases the chances of developing dementia and Alzheimer's disease, sleep disturbances, and even having increased anxiety which can lead to even more health problems. Yes, I have a supportive family and great friends to help me get through, but what about those who do not? It scares me to think of the possibilities of my future and even though I try to keep a positive mind state, it is a lot harder than expected.

As discussed previously, I still suffer from memory problems. Many people including family and friends think that I have selective memory. Selective memory is the term used to describe when your memory only works when you want to remember something. Do not get me wrong, there are plenty of things I do not want to remember such as my god brother's death and the fact that I never got to say goodbye because I was fighting my own battle. Trying to get others to understand that I may not remember certain events or people is like talking to a wall. I repeat myself time after time with people and they seem to let it go in one ear and out the other. One particular story is when a guy, who took me out on dates, tried to get me to remember every place he took me. He said "We done been to Red Lobster, Cheddars, the movies, and all that." I responded by saying that I did not remember Red Lobster. He replies "You only remember what you want to remember." What I want to say to him and everyone else that says this bullshit is "YOU DO NOT HAVE A TBI, DO NOT SPEAK ON WHAT YOU DO NOT KNOW!!!!!!"

This autoethnography has helped me put all the things I feel and experience on a daily basis into words. Writing in a diary or even telling someone what you feel can be therapeutic but what can compare to telling your story and discovering that you are not alone? Knowing that my

story can get into the hands of just a few individuals makes me smile because you never know who might be the answer to your prayers. One of my prayers is for everyone going through this or experiencing TBI with someone they love is for them to get the help they need free of charge. Another one of my prayers is for media, child professionals, and researchers to be a little more concerned even after diagnosis and immediate treatment. Life does not stop after a TBI diagnosis but it does change. Survivors may have a harder time adjusting to these changes and wonder why their behaviors are different from other people. The media, child professionals, and researchers should all have the responsibility to let these survivors know that they are not alone. Creating support groups and following the child as they get older are just a few suggestions to get started.

REFERENCES

- Anonymous, S. F. (2015). Father figuring: An autoethnography of fatherhood. *Qualitative Inquiry, 21*(1), 11-19. doi:10.1177/1077800414550464
- Centers for Disease Control and Prevention. (2016). *Get the Stats on Traumatic Brain Injury in the United States*. Retrieved from http://www.cdc.gov/traumaticbraininjury/pdf/BlueBook_factsheet-a.pdf
- Centers for Disease Control and Prevention. (2014). *TBI data and statistics*. Retrieved from <http://www.cdc.gov/traumaticbraininjury/data/index.html>
- Cook, Peta S. (2014). 'To actually be sociological': Autoethnography as an assessment and learning tool. *Journal of Sociology, 50* (3), 269-282.
- Corti, K., Reddy, G., Choi, E., & Gillespie, A. (2015). The researcher as experimental subject: Using self-experimentation to access experiences, understand social phenomena, and stimulate reflexivity. *Integrative Psychological & Behavioral Science, 49*(2), 288-308. doi:10.1007/s12124-015-9294-6
- Custer, D. (2014). Autoethnography as a Transformative Research Method. *Qualitative Report, 19*(37), 1-13.
- Dillahunt-Aspillaga, C., Agonis-Frain, J., Hanson, A., Frain, M., Sosinski, M., & Ehlke, S. (2014). Applying a resiliency model to community reintegration and needs in families with traumatic brain injury: Implications for rehabilitation counselors. *Journal of Applied Rehabilitation Counseling, 45*(1), 25-36.

- de Kloet, A. J., Lambregts, S. M., Berger, M. M., van Markus, F., Wolterbeek, R., & Vliet Vlieland, T. M. (2015). Family impact of acquired brain injury in children and youth. *Journal of Developmental and Behavioral Pediatrics, 36*(5), 342-351.
doi:10.1097/DBP.0000000000000169
- Elbogen, E. B., Wolfe, J. R., Cueva, M., Sullivan, C., & Johnson, J. (2015). Longitudinal predictors of criminal arrest after traumatic brain injury: Results from the traumatic brain injury model system national database. *The Journal of Head Trauma Rehabilitation, 30*(5), 3-13. doi:10.1097/HTR.0000000000000083
- Ellis, C. (2004). *The Ethnographic I*. Walnut Creek, CA: AltaMira.
- Farley, Y. R. (2007). Making the connection: Spirituality, trauma and resiliency. *Journal of Religion & Spirituality in Social Work: Social Thought, 26*(1), 1-15.
doi:10.1300/J377v26n01_01
- Farrell, L., Bourgeois-Law, G., Regehr, G., & Ajjawi, R. (2015). Autoethnography: Introducing 'I' into medical education research. *Medical Education, 49*(10), 974-982.
doi:10.1111/medu.12761
- Ganesalingam, K., Yeates, K. O., Ginn, M. S., Taylor, H. G., Dietrich, A., Nuss, K., & Wright, M. (2008). Family burden and parental distress following mild traumatic brain injury in children and its relationship to post-concussive symptoms. *Journal of Pediatric Psychology, 33*(6), 621-629. doi:10.1093/jpepsy/jsm133
- Hall, H. R., Neely-Barnes, S. L., Graff, J. C., Krcek, T. E., Roberts, R. J., & Hankins, J. S. (2012). Parental stress in families of children with a genetic disorder/disability and the

- resiliency model of family stress, adjustment, and adaptation. *Issues in Comprehensive Pediatric Nursing*, 35(1), 24-44. doi:10.3109/01460862.2012.646479
- Humphreys, I., Wood, R. L., Phillips, C. J., & Macey, S. (2013). The costs of traumatic brain injury: a literature review. *ClinicoEconomics and Outcomes Research: CEOR*, 5, 281–287. <http://doi.org/10.2147/CEOR.S44625>
- Ilie, G., Mann, R. E., Hamilton, H., Adlaf, E. M., Boak, A., Asbridge, M., & Cusimano, M. D. (2015). Substance use and related harms among adolescents with and without traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 30(5), 293-301. doi:10.1097/HTR.0000000000000101
- Kirk, S., Fallon, D., Fraser, C., Robinson, G., & Vassallo, G. (2015). Supporting parents following childhood traumatic brain injury: A qualitative study to examine information and emotional support needs across key care transitions. *Child: Care, Health and Development*, 41(2), 303-313. doi:10.1111/cch.12173
- Lax Pericall, M. T., & Taylor, E. (2014). Family function and its relationship to injury severity and psychiatric outcome in children with acquired brain injury: A systematized review. *Developmental Medicine & Child Neurology*, 56(1), 19-30.
- Linden, M. A., Braiden, H., & Miller, S. (2013). Educational professionals' understanding of childhood traumatic brain injury. *Brain Injury*, 27(1), 92-102. doi:10.3109/02699052.2012.722262
- Marsh, J. L., Brown, A. J., & Ebrary, I. (2012). Faith, resistance, and the future: Daniel Berrigan's challenge to catholic social thought (1st ed.). New York: Fordham University Press.

- McKinlay, A. (2014). Long-term outcomes of traumatic brain injury in early childhood. *Australian Psychologist, 49*(6), 323-327. doi:10.1111/ap.12084
- Murphy, M. P., & Carmine, H. (2012). Long-term health implications of individuals with TBI: A rehabilitation perspective. *Neurorehabilitation, 31*(1), 85-94.
- Neuman, M. E. (2011). Addressing children's beliefs through fowler's stages of faith. *Journal of Pediatric Nursing, 26*(1), 44-50. doi:10.1016/j.pedn.2009.09.002
- Pappadis, M. R., Sander, A. M., Struchen, M. A., Leung, P., & Smith, D. W. (2011). Common misconceptions about traumatic brain injury among ethnic minorities with TBI. *The Journal of Head Trauma Rehabilitation, 26*(4), 301-311.
doi:10.1097/HTR.0b013e3181e7832b
- Parker, S. (2009). Faith development theory as a context for supervision of spiritual and religious issues. *Counselor Education and Supervision, 49*(1), 39-53.
doi:10.1002/j.1556-6978.2009.tb00085.x
- Pierson, E. E., & Noggle, C. A. (2010). Pediatric TBI: Prevalence and functional ramifications. *Applied Neuropsychology, 17*(2), 81-82. doi:10.1080/09084281003708795
- Popernack, M. L., Gray, N., & Reuter-Rice, K. (2015). Moderate-to-severe traumatic brain injury in children: Complications and rehabilitation strategies. *Journal of Pediatric Health Care, 29*(3), 1-7. doi:10.1016/j.pedhc.2014.09.003
- Potter, J. L., Wade, S. L., Walz, N. C., Cassedy, A., Stevens, M. H., Yeates, K. O., & Taylor, H. G. (2011). Parenting style is related to executive dysfunction after brain injury in children. *Rehabilitation Psychology, 56*(4), 351-358. doi:10.1037/a0025445

- Powell, T., Gilson, R., & Collin, C. (2012). TBI 13 years on: Factors associated with post-traumatic growth. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, *34*(17), 1461-1467. doi:10.3109/09638288.2011.644384
- Prigatano, G. P., & Gray, J. A. (2007). Parental concerns and distress after pediatric traumatic brain injury: A qualitative study. *Brain Injury*, *21*(7), 721-729.
doi:10.1080/02699050701481605
- Raj, S. P., Wade, S. L., Cassedy, A., Taylor, H. G., Stancin, T., Brown, T. M., & Kirkwood, M. W. (2014). Parent psychological functioning and communication predict externalizing behavior problems after pediatric traumatic brain injury. *Journal of Pediatric Psychology*, *39*(1), 84-95. doi:10.1093/jpepsy/jst075
- Rassovsky, Y., Levi, Y., Agranov, E., Sela-Kaufman, M., Sverdlik, A., & Vakil, E. (2015). Predicting long-term outcome following traumatic brain injury (TBI). *Journal of Clinical and Experimental Neuropsychology*, *37*(4), 354-366.
doi:10.1080/13803395.2015.1015498
- Reilly, R. C. (2013). Me and goldilocks...searching for what is "just right" in trauma research: An autoethnography. *Qualitative Report*, *18*(47), 1-11
- Roscigno, C. I., & Swanson, K. M. (2011). Parents' experiences following children's moderate to severe traumatic brain injury: A clash of cultures. *Qualitative Health Research*, *21*(10), 1413-1426. doi:10.1177/1049732311410988
- Roscigno, C. I., Swanson, K. M., Vavilala, M. S., & Solchany, J. (2015). Children's longing for everydayness: Life following traumatic brain injury in the USA. *Brain Injury*, *25*(9), 882-894.

- Ryan, N. P., Anderson, V., Godfrey, C., Eren, S., Rosema, S., Taylor, K., & Catroppa, C. (2013). Social communication mediates the relationship between emotion perception and externalizing behaviors in young adult survivors of pediatric traumatic brain injury (TBI). *International Journal of Developmental Neuroscience*, 31(8), 811-819. doi:10.1016/j.ijdevneu.2013.10.002
- Ryan, N. P., Hughes, N., Godfrey, C., Rosema, S., Catroppa, C., & Anderson, V. A. (2015). Prevalence and predictors of externalizing behavior in young adult survivors of pediatric traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 30(2), 75-85.
- Schachar, R. J., Park, L. S., & Dennis, M. (2015). Mental health implications of traumatic brain injury (TBI) in children and youth. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 24(2), 100-108.
- Stancin, T., Wade, S. L., Walz, N. C., Yeates, K. O., & Taylor, H. G. (2008). Traumatic brain injuries in early childhood: Initial impact on the family. *Journal of Developmental and Behavioral Pediatrics*, 29(4), 253-261. doi:10.1097/DBP.0b013e31816b6b0f
- Wilbers, L. E. (2015). She has a pain problem, not a pill problem: Chronic pain management, stigma, and the family—An autoethnography. *Humanity & Society*, 39(1), 86-111. doi:10.1177/0160597614555979
- Zibricky, C. D. (2014). New knowledge about motherhood: An autoethnography on raising a disabled child. *Journal of Family Studies*, 20(1), 39-47. doi:10.5172/jfs.2014.20.1.39