
3-10-2019

From Test to Testimony: Resiliency After a TBI Diagnosis

Quanisha Miffin

East Carolina University, davisq09@students.ecu.edu

Archana V. Hegde

East Carolina University, hegdea@ecu.edu

Paige Averett

East Carolina University, averettp@ecu.edu

Natalia Sira

East Carolina University, siran@ecu.edu

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>



Part of the [Family, Life Course, and Society Commons](#), [Quantitative, Qualitative, Comparative, and Historical Methodologies Commons](#), and the [Social Statistics Commons](#)

Recommended APA Citation

Miffin, Q., Hegde, A. V., Averett, P., & Sira, N. (2019). From Test to Testimony: Resiliency After a TBI Diagnosis. *The Qualitative Report*, 24(3), 513-531. <https://doi.org/10.46743/2160-3715/2019.3773>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.



From Test to Testimony: Resiliency After a TBI Diagnosis

Abstract

Autoethnographic research is a relatively new means of gathering data on oneself to connect to research and theory while advocating for change within a policy, law, and/ or environment. In this autoethnography I will recount the experience of my traumatic brain injury (TBI) diagnosis following a car accident and present a few implications for the professionals and members of the society at large surrounding the issue of TBI such as the need for awareness and understanding as well as the importance of therapy and other forms of care within different cultures. When I was first diagnosed, many people did not know what TBI was, what it stood for, or what symptoms could result. Although research has progressed with this diagnosis, there is still a long road ahead. The first step to change is recognizing that there is a problem. After the problem is recognized, the solution can begin.

Keywords

Autoethnography, TBI, Resiliency, Spirituality, Family

Creative Commons License



This work is licensed under a [Creative Commons Attribution-Noncommercial-Share Alike 4.0 International License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

Acknowledgements

Quanisha would personally like to thank God for making all things possible. She would like to dedicate this to her son, Khalil Miffin. "Mommy loves you so much!" She would like to thank her husband, Charles Miffin, and her family (especially her mom, Sherrie Spellman, her stepdad, Darnell Spellman and her dad, Milford Creecy) for their support, insight, and challenging her to be the best that she can be. She wants to send a huge acknowledgement to her team of excellent professors who pushed her beyond what she thought was possible. Dr. Hegde, Dr. Averett, and Dr. Sira, thank you so much for your guidance and encouragement through this process. Quanisha also wants to say, "Thank you Rachael Holiday for your insight into correcting and expanding ideas. Rest in peace Grandma ReeRee, keep smiling down on me."

From Test to Testimony: Resilience After a TBI Diagnosis

Quanisha Miffin, Archana V. Hedge, Paige Averett, Natalia Sira, and
Rachael Holiday

East Carolina University, Greenville, North Carolina, USA

Autoethnographic research is a relatively new means of gathering data on oneself to connect to research and theory while advocating for change within a policy, law, and/ or environment. In this autoethnography I will recount the experience of my traumatic brain injury (TBI) diagnosis following a car accident and present a few implications for the professionals and members of the society at large surrounding the issue of TBI such as the need for awareness and understanding as well as the importance of therapy and other forms of care within different cultures. When I was first diagnosed, many people did not know what TBI was, what it stood for, or what symptoms could result. Although research has progressed with this diagnosis, there is still a long road ahead. The first step to change is recognizing that there is a problem. After the problem is recognized, the solution can begin. Keywords: Autoethnography, TBI, Resiliency, Spirituality, Family

An autoethnography is a qualitative method that uses the researcher as the source of data. Custer (2014) describes autoethnography as a method that involves three key elements. Autoethnography helps researchers transform their views of the past into useful information for the future. It can help researchers become vulnerable by reflecting on the naked truth that is embedded in past experiences and memories. Lastly, autoethnography can create and welcome change through subjectivity. Buckley (2015) suggests that autoethnography is one form of research that allows researchers to be participants of their own research. Other self-evaluation methods that allow researchers to be participants of their studies include autobiographies and narratives. Unlike those other qualitative forms of research, autoethnography allows researchers to examine themselves in relation to culture around them. This relation to culture and evaluation of self allows researchers to examine the reasoning and cause of resulting feelings, thoughts, and actions (Jones, Adams, & Ellis, 2016). For example, I am an African American, young, Christian female who lives in a small city with little to no awareness about traumatic brain injury (TBI); therefore, my cultures include being an African American, being young, being a female, being a Christian, and living in a small urban area. The examination of myself and the reasons/causes of my thoughts are all somehow connected to all the cultures I have listed. Although someone may share my feelings about TBI, no one will have the same connections I have with my different cultures.

Other forms of research aim to protect their participant's feelings of embarrassment and fear by transforming their personal experiences into quantitative data or masking them by sticking to prompts. Autoethnography is a very vulnerable research tool because researchers must recap their personal experiences and tell their truths which may result in self-harm or bring back very painful memories in order to gain a bigger reward, change in culture (Allen-Collinson, 2013). I cannot lie, there have been many times during this research process that I had to cry, questioning whether I really wanted to do this; I even thought of not publishing at all. It took a lot of encouragement from my family, my husband, and my professors for me to do this. Some of these painful memories and effects of my TBI have resulted in even more memory loss and overthinking. There are many times that I cannot remember important people,

events, or details of my life. I get so frustrated inside and then I try to find a coping mechanism such as ignoring or finding something else to think about. But honestly, what hurts the most is that I try to take as many pictures as I can with my family, especially my son, because I cannot ever be sure that I can remember certain events as the days go by. I chose autoethnography to get to the bottom of my frustration with this lifelong illness because it is the stronger choice of research, in my opinion, to use for extreme trauma and other life-changing experiences.

According to Ellis (2004), an autoethnography is a work about personal experience and the relationship of this experience to the larger culture. Autoethnographic storytelling often comes from and causes moments of personal change and insight. In this particular autoethnography, I choose to concentrate on two important parts of my story: my car accident and how it has impacted my present life. I started to collect data by asking my parents questions regarding the accident. Although autoethnographies are primarily based on self, they may include others to help describe and explain a recalled event. Because I was only 6 at the time of the accident and my TBI resulted in some memory loss, I had to ask my parents (mother, father, and stepfather) questions during this study to lend insight about the event surrounding my accident.

My mother and father, never married, had broken up when I was 5 years old. My father had never been an absent father, so once he received the news of the accident, he was by my mother's side during the whole process of recovery. After my recovery and some years later, my mother met my stepfather and he was told about my condition and things he may experience while in my life. I wanted to use my stepfather's perspective on my behaviors and actions in my later years of life. I asked my mother, my father, and my stepfather about the events that were centered around the accident, during the accident, after the accident, and the beginning of the recovery process in Charlotte Rehabilitation Center.

Because my mom was the person who saw in full detail what happened during the accident and after, she was the one who was interviewed first. After gathering her insight about the accident, I somewhat compared and contrasted everything she told me with what my stepdad and dad remembered. In other words, for some events and details my mother did not remember or were too painful to discuss, my stepdad and dad filled in (e.g., my birthday party in the hospital). My dad told me about what happened on my birthday after I came out of the coma. As you will find out later in this research, my birthday (June 19) was only a few days away from the accident, so the doctors, nurses, and my parents gave me a little party in my room with a cake and balloons. I did not know what was going on because I had just come out of a coma, so I used my dad's perspective on how I responded to my party. My stepfather told me about how he had to interact with me after he met my mom. He had to be informed of my condition and what he was not allowed to do with me such as ride on roller coasters and jump on a trampoline.

According to Ellis (2004), family members' perspectives may be included without the need for any official consent, provided they readily agree to participate in the research. Whereas ethnography and quantitative data may involve a researcher observing as a disguised individual or as a researcher, autoethnography is based on the researcher being his or her own observer (Corti, Reddy, Choi, & Gillespie, 2015). Everything that happened after the first week at Charlotte Rehabilitation Center was my own research and perspective. What I mean by everything is all the thoughts, reactions, and feelings I felt after I recovered from rehab were of my own.

The next step I took to collect data was to review my medical records. My medical records provided in full detail how my brain was impacted and all the therapies I went through while in Rehab. After collecting the initial data from those sources while starting to write my thesis, I recalled my own personal memories from this tragedy and opened up to my most vulnerable place by expressing my emotions of regret, fear, sadness, and frustration. Some of

the people I opened up to and who witnessed my emotional rollercoaster were my professors at the time, a few classmates, and my family. In relation to my own vulnerability, I researched articles about childhood TBI and lifelong effects.

I changed my mind about being a participant of my own research after researching a few articles. I decided that I wanted to interview a woman from my hometown who had been recently diagnosed with TBI from a car accident. I did not want my own story to be told anymore because I did not want to be reminded of the reason I feel the way I do today. I had talked to the woman's father over the phone and was even gathering information about her personal experience. But something did not feel right once I started gathering her information.

I had prayed to God and asked some of the people closest to me what they thought I should do as far as a research method. Some of those people include Dr. Archana Hegde, Dr. Natalia Sira, and Dr. Paige Averett. Dr. Hegde was my thesis chair. In order to graduate for my Master's degree, I had to do a thesis which came in the components of a major research paper and presentation on why the research was important. Dr. Hegde pushed me to think outside of the box and do something different than what my peers were doing at the time. All of my peers were doing mostly quantitative methods and getting others to fill out surveys. I am not saying that their research is not valid or interesting. I just wanted my research to stand out and be unique in the sense that no one could come up with the same results as mine.

My situation, even though many have been diagnosed with TBI, is unique. Uniqueness deserves its own shine. Dr. Sira helped me form my theory section by helping me find theories that do not, in my opinion, get a lot of attention in most research. In my college career, I was always presented with theories by Erikson, Piaget, and more common researchers. When gathering my data, Dr. Averett (Averett, 2009) had sent me a copy of her autoethnography about Wonder Woman. It really opened my eyes up to see the potential my paper could have if I believed in it. I still think about how she described the aisles of the stores she went through to find Wonder Woman and she could not find her in her research. This opened my eyes up to the fact that my story could somehow be that Wonder Woman that needed to be found in an aisle to let a little girl know that there was someone who she could look up to. The hero does not have to be a male figure who has superpowers, but it could be a woman who found her inner strength by telling her story. Just like Dr. Averett could not find Wonder Woman in any aisles, I could not find any autoethnographies about TBI. I could not find TV infomercials or magazines with current information about TBI. I could not find any cartoon characters or superheroes with the condition either! This spoke volumes to me because it sent the message to those suffering from it that they do not matter. Imagine a little boy wanting to be like Batman or Superman. Of course, most fans know that Superman's downfall is kryptonite while Batman uses more of his gadgets than his own strength. My point is, it is very hard to be fully accepted and understood when there is nothing in the media or the community that makes the condition known. I finally came to the conclusion to tell my own story because of a spiritual vision I had. God told me that my story would impact others to bring change in my community. God told me to trust myself and push myself harder than ever before, and that is what I did. I wanted everyone who ever experienced having TBI to never feel alone and tell their own stories, face their own realities, and potentially heal themselves. I wanted my story to reach a doctor, medical professional, family advocate, or just someone who could push for change in our culture. I wanted this research to be a form of my testimony to my son that no matter what you go through in life, your story can help make a difference and change the world one step at a time.

After this epiphany, I went back to the interviews I had with my parents and combined my own perspective with the literature I found. A lot of articles I found told of how parents felt that they did not have the knowledge or understanding to care for their child with TBI or what happened after the release from the hospital (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015).

I felt that there was something missing that needed to be told: the victim's perspective. How can a doctor, nurse, medical professional, or even the parents tell you what the victim is truly feeling even after recovery? This is why I decided to combine the literature I found with what needs to happen based on my own experience living with TBI. I could have let my passing grade for my thesis speak for itself, but this story and research can do so much more in the right hands. Getting this published is, I believe, the best way for this research to go beyond an "A" in a thesis course.

Defining Key Concepts

Pediatric TBI, or traumatic brain injury, is an acquired injury to the brain due to a traumatic event to a 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, 2016). Rassovsky et al. (2015) state that traumatic brain injury is the most common cause of brain injury resulting in long-term mental and physical disability. Motor vehicle crashes continue to be the leading mechanism of injury for death and disability in pediatric TBI (Popernack, Gray, & Reuter-Rice, 2015). Taylor, Bell, Breiding, and Xu (2017) state that a total of approximately 2.8 million TBI-related emergency department visits, hospitalizations, and deaths occurred in the United States in 2013. 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 (CDC, 2016). For these and other reasons, we should be more attentive to the needs of TBI patients and their families. The leading causes of TBIs in this recent research are falls, motor-vehicle accidents, and self-harm. About 21,308 children aged 5-14 were hospitalized due to TBI related injury in 2013 (Taylor et al., 2017). Lalonde, Bernier, Beaudoin, Gravel, and Beauchamp (2018) state that young children are more susceptible to brain injury because their skulls are very thin and malleable while their cerebral sutures are unfused. Children with traumatic brain injury are likely to have a harder time developing new skills because of the limited range of acquired skills learned in early childhood. Certain skills that require the strength of my right side are still harder for me because of the post concussive effects of my TBI. There are times when I use my left hand more to push certain items or open something even though I am right-handed.

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 (Ganesalingam et al., 2008). Yes, I still suffer from memory loss of past events and even more recent events. I still suffer from headaches, and I have to turn all the lights off in a quiet room (noise and light sensitivity) and lie down until it goes away. Medication will not help me in those situations. I suffer with depression and anxiety also. I have not been psychologically evaluated yet because of insurance problems, not wanting to be labeled, and having faith that God will take it away. But when I truly think about it, God created people to be in certain positions to help others. So why do I fear being labeled? Am I just making excuses to feel better about my situation so I will not have to face the diagnosis from a psychologist or psychiatrist? I remember learning about something called the self-helplessness theory in my undergrad career that pretty much states that people give up or give in when they feel hopeless, so they just accept their fate. Maybe I have this fear that if I get a proper diagnosis, I will just accept it and not ever feel whole again. But isn't the first step of healing recognizing that there is a problem in the first place?

While doing my research, I was shocked to learn about the following statistics. Almost 60% of children with TBI develop psychiatric disorders after injury. These disorders include but are not limited to attention-deficit disorder, bipolar disorder, and depression. Other short-term effects of TBI include depression, aggression, social isolation, and heightened dependence on caregivers (Dillahunt-Aspillaga et al., 2014). Behaviorally children may experience difficulties in generalization, inappropriate behavior, stimulus-bound behavior, recurrent loss of control, and unrestrained anger. Various emotional problems have been observed such as decreased apathy and extreme emotional reactions (Rassovsky et al., 2015). Childhood TBI can cause death, improper functioning, and create great stress on the child and the family (Potter et al., 2011). Lalonde et al.'s (2018) study concluded that the parent-child relationship was affected by the child's traumatic brain injury. Most of the children in their study did not have a cooperating or loving relationship with their parents after their diagnoses.

My relationship with my parents has not changed. In fact, it has become stronger because of this experience. We have all valued life a little more because we never know when it will be our time to leave so we show each other true love every day. I have always shown them the upmost respect and the love is unconditional on both sides. But the other post-concussive symptoms and disorders I can closely relate to. There are times I can be sitting in a room all by myself and cry/scream for no apparent reason. I remember one day, my husband came home from work and I was crying. He asked me what was wrong, and I honestly couldn't tell him what caused the crying. No, that is not just a typical "woman" thing because of my hormones or emotions. That is something that happens at least once a week in our home.

Another occasion was during high school. I came home with my interim report and was so nervous to show my grades to my mom and my stepfather. I know, what kid doesn't get nervous showing their parents their grades? After the accident, I was placed back in public schools and every grade that followed was an A-B average. In one particular class in high school, I was so nervous about Chemistry that as soon as I opened the report in front of my parents, I cried. I do not mean the "a few tears were shed" type of crying. I mean a cry that came from extreme hurt and disappointment. It took close to an hour for my parents to calm me down and to let me know that they were still proud of me.

After my diagnosis of having a TBI, doctors were almost sure that I would have to be put in special education classes and have to be dependent on my parents for the rest of my life so that is where my determination and strive come from. I aim to prove them wrong every day. Yes, I graduated college with a Bachelor's and a Master's degree, but I still feel the need to prove them wrong so I constantly push myself to go above and beyond expectations, even to the extreme of fatigue and depression.

When a child has been diagnosed with a TBI, parents, caregivers, and families all have to find the ability to increase their resources to cope efficiently. My family, my husband, and even my friends have had to constantly encourage me and even give me "tough" love at times because I fall so deeply into self-pity. But until I started doing this research, I never sat down to think about how they need resources to cope with me. They have never made me feel like a burden or a problem for them, but I know for a fact that I can be a handful. Putting the stress and coping that they had to face and are still facing today into theoretical frameworks will help to relate my experience and my family's experience with science and the outside culture. I felt very strong about the following theories I learned in my college career to use in this research.

Literature Review

When gathering my research, I logged into my college databases as well as Google Scholar and the first term I researched was traumatic brain injury. There were a lot of results, so I decided to narrow it down a little. I then researched childhood TBI. Again, there were

many results. Some research within that category told about the parents' perspectives of what they thought TBI meant for their child while others were more observational methods that told about what symptoms were observed as the child got older. I used some of that research to form this research, but the most important search term is what brought this paper to what it is today. When I searched for autoethnography and TBI, there were no results. Although autoethnographies have centered on many ideas and experiences, there have been no longitudinal autoethnographies reporting on the effects of traumatic brain injury. No autoethnographies have addressed the issues and experiences of the victim who was diagnosed with traumatic brain injury. When children read a book or watch a TV show, they can get excited when there are people who share their same interests or who look like them. In this sense, those diagnosed with TBI may not speak out about it or write about it because it is not common in their community, online, on television, or anywhere around them. It is important to look at each unique story of diagnoses such as TBI because we learn by observing others. One story may tell you what another story did not. I want this story to help others speak out so that there can be more unique and in-depth stories of what TBI actually means to the victim, not the parents, the doctors, or others. 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 such as interviewing to identify effects of pediatric TBI on victims and their families (Kirk et al., 2015). The interviews used in these studies asked the parents of the study about their experiences and their unmet needs after their child's release from the hospital but failed to get the victim's perspective or follow up with the families to see the effects of traumatic brain injury over time (Prigatano & Gray, 2007).

My Study

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 the outcomes which have impacted my past and present. I will discuss the impact this incident had on my life and my current experiences associated with this trauma as well as make an attempt to extract and generalize what I have learned to shape and change societal views. My aim is to inform policy and practice at the governmental/organizational level and benefit other individuals who have or might experience similar trauma. After the time of the accident, it was the hospital's and rehabilitation's procedure to care for me until I was functional enough to go home. Functional, in my opinion, means being able to be as close to "normal" as possible. After they had determined that I could walk and talk properly, they sent me home to my family. I see that even in today's society. But when you truly think about the meaning of normal, does it mean the average or is it based on one's subjectivity? Just because I could walk and talk or win a few memory games in recovery does not necessarily mean I was back to my normal. Of course, after people experience trauma, they will most likely change but it is not fair for doctors, nurses, rehab techs, or anybody else involved with children and their families during their trauma not to check on them over the years. Some may think the parents should have reached out for help or the patient should have sought out more therapy. What if they could not afford it? What if they were in denial about how they were handling a diagnosis because they had other life issues going on? I have had many other things happening in my life that have kind of distracted me from my real issue. Sometimes I think I am strong enough to handle it on my own. But people who God has assigned to be in the medical field need to know that people can share the same exact thoughts as I do and be too scared or shameful to ask for help even years after they were diagnosed. I will begin by defining what TBI is and its effects.

Theory Framework

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 (Dillahunt-Aspillaga et al., 2014). This model is centered around a combination of ecological and developmental perspectives that focus less on family deficiency and more on family competency.

The model itself begins with an examination of the family stressor (Hall et al., 2012). The Resiliency Model of Family Stress, Adjustment, and Adaptation measures the power of the stressor by determining family vulnerability, baseline functioning patterns within the family, resistance resources (including communication, patterns of functioning, and supports), family appraisal of the stressor, and problem-solving/coping strategies of the family (Hall et al., 2012). The model results in labeling a family either (a) bonadjusted, (c) maladjusted, or (c) in crisis (Hall et al., 2012). A family in bonadjustment has progressed through the stressor without difficulty, while a family in maladjustment is experiencing difficulty in obtaining stability. A family in crisis needs resources and modifications to family functions (Hall et al., 2012). Some parents assessed within the Resiliency Model of Family Stress, Adjustment, and Adaptation reported enhanced personal and spiritual growth, sense of purpose, and improved relationships due to the stressor of having a disabled child (Hall et al., 2012). This model has shown that family perception of stressors reflects how well the family can adjust (Spina, Zivani, & Nixon, 2005).

Families may use many types of resources to establish resiliency in crisis. Resources can be financial, spiritual, and social in nature. My family used spirituality as a primary means of coping and an anchor of resiliency throughout this experience. 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 establish meaning in their lives and obtain rules of morality. In experiences of trauma, one may rely on spirituality to find purpose in suffering. I cannot lie, no, I do not understand why I had to endure the trauma I have gone through and still going through. I do not understand why I had to lose someone very close to me during this accident. My grandmother, before she passed, always told me to trust in God's plan and not lean to your own understanding. She always said that he has a bigger purpose for our lives. In some way, I feel that God is trying to make me stronger and the death of someone close to me is his way of telling me to value life even more. Kruidenier (2017) defines faith as the substance of things hoped for. Many people like my family relied on their faith in order to find a purpose in their pain and find hope in things unseen. Kruidenier (2017) also suggests that people use their spirituality as an individual and personal experience. In other terms, the gathering of individuals in a group setting in a church or other setting is merely religion while the thought and feelings in someone's heart/mind, also known as subjectivity, is unique. My family used prayer, gospel songs, and bible-based scriptures in a group setting to cope with my trauma but each of them had an individual and personal relationship with God to fulfill their individual needs. For example, while all of my family prayed for healing, each one had a personal exchange and emotional outlet with God. While one may have prayed for my healing in exchange for them being saved, another was angry with God for this event happening in the first place while still praying for my healing.

Fowler's Model of Faith Development includes four stages associated with spirituality in 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 in which children develop trust due to their environment and their caregiver's behaviors. The mythic/literal stage, sometimes called the intuitive/projective stage,

describes a stage in which the child's thinking is fantasy-filled and fluid. The synthetic/conventional stage refers to the period when a child develops concrete operational thinking so he or she can understand cause and effect, and narrate stories (Parker, 2009). The individual/reflective stage is when children reflect on their belief system as a system and separate symbols from their meanings (Neuman, 2011). de Kock (2016) suggests that the mythic/literal stage was the age appropriate stage for me at the time of my accident. This stage is labeled for 3- to 7-year-old children who can believe in things not seen because they do not have the ability to know what is real and what is not just yet. These children mostly go off of what their parents or cultures have taught them about God and faith instead of actually believing themselves. At that point in my life, I was a typical 6-year-old child who wanted to please my family, so I did what was expected of me as far as behavior, grades in school, and participating in religious gatherings such as prayer and attending church. The individual/reflective stage requires older children/young adults to critique their beliefs, feelings, and values to separate their experience with God from what they were taught by their families/culture (de Kock, 2016). At this point in my life, I am fully aware that there is a God, and nobody can influence me otherwise based on my personal experiences and not just what someone has taught me. I know that there are people who have other religious affiliations or who do not believe in God at all and I respect them, but no one can convince me that there is another God or no God at all. My grandmother, my mother, and other people have taught me how to pray, explained who God was, and have introduced me to the Bible, but none of them or their teachings are the reasoning behind my faith in God today. My faith in God primarily comes from all that he has done for me and my family despite the hardships we have had to endure. One of the hardest challenges we have ever faced is the car accident that led to the loss of a loved one and the fight for my life. Here is my story.

My Story

In the beginning of June 1998, my mother, her former best friend (my godmother), her two kids (my god siblings), my cousin, and I all loaded into a 1993 Ford Probe to take a trip to Washington D.C. On June 15th we went around the downtown area of Washington, DC to visit the Lincoln Memorial and all the museums surrounding it. After a few hours, we headed back towards my godmother's parents' house. We were heading northbound on Route 1 in Beltsville, Maryland. While my godmother was driving, she attempted to make a left turn onto Lincoln Avenue when an olive green Ford Explorer hit us on the passenger side between 6:00-6:45 pm. Our vehicle was turned 360 degrees twice in the middle of the road. 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. She said that the mother in her wanted to believe that everybody was going to be okay but the human in her told her that something bad was going to happen. She was in a bit of shock, but she had to put her own needs aside to calm my godmother down and get help. My mother told me that my godmother 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 pass her. She still believes that shadow to be our family's guardian angel. Onlookers all jumped out of their cars to give us blankets and offer emotional support until the ambulances arrived. My mother and godmother went to the adult hospital while my god brother and I were taken to the Children's National Medical Center. Hours went by before our parents knew what was going on with us. According to doctors who talked to my mom after her release from the hospital, I went into shock and went into a coma after getting out of the ambulance.

When my mother and my godmother walked in to our hospital room, my god brother was in the first cubicle that they saw. Blood covered his respirator and blood was all over his face. According to his brain activity levels, my god brother had very little activity. I was on a respirator, a feeding tube, and had an IV. On June 16, 1998, my family (including my father, my other god mother and her boyfriend, my maternal grandparents, and my aunt) arrived at the hospital.

In the waiting room, my family heard one of the loudest screams they had ever heard. All they heard was “NOOOOOOOOO!!!! This can’t be true! That’s a lie! NOOOOO!!!!” They later determined that the scream was from my godmother as she learned my 5-year-old god brother died. A few tears were shed before one doctor had to come and talk to my parents about my condition. The doctor reported that I had a traumatic brain injury, a condition that can occur when the brain experiences some sort of severe trauma that could result in disability and complications. He went on to tell them that the next few hours would be critical, and although a full recovery was possible, I might not be able to walk or talk properly, and I could develop learning disabilities.

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. Essentially, I had bleeding in my brain that resulted in my inability to walk, talk, and function properly and damage to my liver that healed predominantly 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 progress. After opening my eyes within the next few days, I only wanted my mother and father around me. I was scared of everyone else, constantly screaming whenever doctors or other people came to visit. I had trouble sleeping and would wake up during the night screaming. Because I still did not have proper functioning in my right side, I had to start wearing diapers again. I was using one-word sentences and had to be handfed after my feeding tubes were removed. My parents told me that they cried every day and prayed for a miracle. They were mostly in shock because they remembered me being able to walk and talk like a normal child no less than a week before the accident. They said that they did what they had to do because they could not give up hope that I would one day come out of the state I was in.

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 of my cousins brought me a doll baby (that I still have) named “Jingles.”

After my care at the Children’s Hospital in Washington, DC, 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. As I stated before, my father had never been an absent parent, but my mother was my main source for this recovery process. I lived with her all my life and she took primary care of me. She could not afford my medical costs even with the insurance she had as a teacher at that time. My father lived in South Carolina, so after I was released from the Rehabilitation Center, I was in my mother’s care. We arrived at Charlotte’s Rehabilitation Center on July 1, 1998. 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 received speech therapy, occupational therapy, and physical therapy for approximately 2-3 hours a day (all of which were more intense than the care I received in Washington DC). I had to be active with play equipment, improve memory with memory card games and recall events in a story, along with other similar activities. My parents

were not allowed to participate in any of this, but I got very close to one nurse in particular. She acted as my mother figure while my own mother could not be there. She brought me banana nut bread a few times and came to sit with me whenever she had free time. It really hurt when I had to say goodbye to my parents every night, so this nurse helped me feel safe and secure when my parents had to leave. It felt like she paid close attention to me and always wanted to know if I was okay. I also had Jingles there with me to hold at night when I had to say goodbye to my parents. Jingles was, at that time, my connection to my family when they were away. Jingles reminded me that there was a world outside of the Rehab center and people waiting for me to get better. Midway through my stay there, my parents were allowed to come watch me during therapy and see my progress.

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!" Now my grandfather was not the type to cry or at least not show it around others, but that day he did not care who saw him cry. My cousin (the one in the accident with me) was the first to run and hug me when I got out of the car. He typically got on my nerves before the accident. My mother always tells me how we used to fight over everything and be mad at each other for hours. But this particular day, we cried and held on to each other for dear life. When I went inside, I saw all the food my family had prepared including fried chicken, turkey wings, collard greens, rolls, sweet potato pie, and sweet tea. Sweet potato pie is one of the best things in God's beautiful earth (in my opinion). My grandmother knew that that was, and still to this day, my favorite dessert. My grandmother told me that one of my cousins was trying to sneak a piece of fried chicken before my arrival and eat it before being seen. The cousin was caught right before the chicken was about to enter their mouth. Everyone in the house greeted me, hugged me, cried, and thanked God that I was okay. I remember seeing my great aunt, who was blind, smiling when she heard my voice. I even remember my grandmother shouting and saying "Hallelujah, Thank you Jesus!"

Changes had to be made in my environment after returning to school. 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. 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. After a few years of observation, the doctors I saw felt no need to continue scans of my brain and there were little to no checkups from them or anyone in the medical field. When I think back, everyone probably assumed that everything was fine and that I would function normally as a typical child. What they failed to realize is that TBI can have life-long effects. Maybe they did inform my mother about what could possibly happen down the line, but they have not offered mental services such as counseling or family therapy over the years. My hometown and areas that I have lived in are still culturally insensitive to TBI. I have been to a number of doctors' offices, health departments, and community support buildings and have not seen anything concerning TBI. Most people I ask in my community do not know what it is or what it means for someone who suffers with it. Even my husband has had to research it in order to better understand me.

When asked how they made it through these changes they report their faith in God, prayer, and the support of their relatives and friends is what helped them survive this tragedy. My parents had to rely on family, friends, and my pediatrician to keep them informed and encouraged about my TBI because there were no local programs or services for TBI survivors

during that time. Both of the Resiliency Model of Family Stress, Adjustment, and Adaptation and Fowler's Model of Faith Development helped me to better understand and reflect on my experiences (Hall et al., 2012; Neuman, 2011). The birth of my son has led me to reflect on this experience more and get it published because I cannot let the effects I am still currently dealing with defeat me. I have to live for myself but even more importantly, for him. I want him to grow up and know that mommy did not let her fears or disappointments defeat her. I want my son to read this one day when I am not able to tell him and be encouraged to face his truth and overcome his troubles. I want to feel happiness knowing that I can still change my current state of mind instead of living in regret and frustration. Lastly, I want others to fight for their purpose. Maybe my purpose on this earth is to encourage others through my testimony. My parent's experience of witnessing my injury and recovery was horrendous. When someone decides to become a parent, the individual needs to commit their own time and resources to a new and vulnerable life. I did not understand this in full detail until I became a mother myself. My mom always told me you will understand when you become a parent during the times that I wanted things my way and she would not let me get my way. Or even the times I wanted to go places and she kept me in the house to protect me from unseen dangers. When my son started to become mobile, I was so scared about him falling and hurting himself. Everyone around me would say, "Oh, he's just a boy" or "He's alright" when I went to comfort him. But I truly believe that a mother's love is like no other even if it is just a fall. When it comes to bigger things such as a car accident, I could not imagine the hurt, the pain, or frustration my mother faced. You cannot truly protect your children from those dangers or after effects, so you feel a sense of guilt for not being their protector. As a mother, your child depends on you for physical resources such as food and water as well as emotional resources such as a sense of well-being and confidence. My mother was faced with a major life blow by trying to comfort her best friend for the loss of her child and be there for me at the same time. My mother had to understand that she was human and only God could perform the miracle she needed.

My crisis left my parents feeling helpless in the care of their own daughter. They were discouraged, angry, and heartbroken. The TBI caused by a car accident was the stressor of our family's resiliency model. Our family's immediate perception of our situation was hopeful and fearful all at once. My parents wanted to do everything they could for me but did not have the knowledge and resources to care for me alone. One of the biggest resources at that time was money. Medical bills are not cheap at all! In fact, in my opinion, it is absolutely ridiculous what someone has to pay when they are the ones suffering, especially for sudden emergencies and unpredictable things like car accidents. As stated before, my mom had to apply for Medicaid because her insurance through her job would not cover the expenses. We were hopeful that I would recover to live a (mostly) normal life and scared of what our lives would look like if I did not fully recover. Our resistance resources included primarily our faith, but also the support we had from our larger family and our community. 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. Our coping strategies were to pray together, communicate openly with each other, abide by the recommendations of our health professionals, and allow our community to stabilize us when our circumstance seemed too large to bear alone. As an African American, I feel that praying has always been our strength to lean on during hard times. Whether it be a financial, physical, or mental circumstance, I was taught in my African American culture to trust God. I may not understand his ways, but I was raised to trust his process. I do not understand why my god brother had to die or why I still suffer from effects of the TBI, but I do know that God has brought me out of it, and I believe he did because he wants me to tell others about the miracles he can perform. Yes, I have depression and anxiety, but I can walk, talk, and function a whole

lot better than before. Not all families or cultures have these rich spiritual resources to draw on when hardships strike.

Data Analysis

Fowler's spirituality theory defines the stages humans go through in connection to faith and life experience. I was too young to truly comprehend what was happening to me and how it would affect my spiritual life as an adult. I was likely in the mythic/literal stage of Fowler's theory, as a 6-year-old who still loved to play make-believe and live in the world my imagination could create for me. My parents, as adults fully formed in their individual faiths, had to trust in their God to see them through tragedy. When I grew up, I was able to reflect deeply and to gain insight into the purpose of this experience.

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 but because I have experienced a life changing miracle. Science cannot explain the progress I have made, in my opinion, through the years because even the doctors at the Washington DC Children's hospital could not explain how I came out of everything I went through. My life could have ended after only 6 years. Instead I was given the opportunity to value life as the gift it truly is. The journey to recovery from TBI was not easy, but I believe that my God has a higher purpose for my life and that He will see me through any struggle I may face. I have learned there is purpose in suffering, and that purpose is the deeper connection one gains to God when trial arises. By no means am I trying to push my faith on anyone but I have to shed light on the fact that I could have been a vegetable, I could have been in special ed classes, I could have been dependent on someone to care for me for the rest of my life but I am a college graduate with a Master's degree, a Bachelor's degree, many certifications, and a bright future ahead of me.

Although I have not seen a psychologist or psychiatrist since my accident, my primary care physician prescribes me antidepressants to help with my mood swings and feelings of anxiety and sadness. Sometimes I feel guilty that I take them because I want my faith to be the only means of coping that I need. I do not take the antidepressants currently, but I have taken them in the past and could imagine myself taking them again in the future. Instead of using medication I try to stay busy with work and spend my time with positive people. But the truth of the matter is, faith without works is dead! I cannot depend on God to fully heal me or to help me cope. I have to seek out ways to better myself. I have to put aside my fear of being labeled or dependent on medications and focus on the bigger picture. As stated before, God created people to help others, so psychiatrists and psychologists are needed. In order to heal, you have to face your truth. My truth is that I need more help. God can only help me if I help myself first. I have been trying to cope through praying, watching inspirational videos, and going to church so far but I must go even further. As a mother and wife, I have to remember that there are people depending on me to care for them. I cannot properly take care of my son or tend to my husband if I cannot take care of my needs first. As a mom in general, it is very easy to lose yourself in daily chores, running errands, and making sure the child/children are well taken care of. As a wife, I cook, clean, and keep the house afloat. My point is there is less time for myself because of the daily responsibilities I have and many other women can relate to. But if the woman's mental health is not up to par, the whole household can come crumbling down because of her role in the family. I refuse to let my anxiety and depression destroy what I worked so hard to have so I must find a solution through therapy and other research-based techniques. This is my whole purpose for doing this research. I want all African Americans, women, moms, wives, and all those suffering from TBI to know that it is okay to ask for help and demand a change in our culture. There needs to be a change in policy for children to be

able to reach out to the nurses and doctors who cared for them during their stay at the hospital. There needs to be a change in policy for the medical team who was with the child during their recovery to give yearly checkups. A financial burden needs to be lifted from the caregivers of those suffering from TBI. More research, media coverage, and overall discussion of TBI needs to be more apparent! Nothing can change until we all speak out!

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 call him home to heaven as soon as he did. Although it is considered unwise to question the motives of God, sometimes I cannot help myself. My despair in finding a reason for his death sometimes makes me feel hopeless. Instead of becoming stuck in my hopelessness, I work to appreciate the life God has granted me and seek to maximize my positive contributions to the world. My faith was not the only faith radically grown through this experience. More people in my community started praying, seeking out God, and asking me to share my testimony. In the African American culture, we believe in sharing our testimonies in church to uplift one another and tell about the goodness of God. I have also been granted many opportunities to discuss with other TBI patients about their own experiences. These connections are extremely meaningful to me and serve to remind me there are many purposes to my suffering.

I experienced immense personal and spiritual growth following my TBI diagnosis, but I hope to also help other patients and care providers better understand how to serve TBI patients. I want them to read my story and appreciate the uniqueness of it and give hope to those suffering. Instead of seeing how all can fit in one category, it is important to let each patient have their personal story. Everyone should listen to the patient and what they need in later years. In my opinion, adjusting to the world outside of the hospital and rehab center, is the hardest transition. This is where more help and research is needed. It is more than just providing physical therapy so the patient can walk again. Emotional and mental adjustment is needed as well after the body has been subjected to trauma. Some symptoms may not even become apparent until years after the TBI diagnosis. I do not remember most of my childhood but my mom reports me as being the closest thing to normal at the time before the accident. After the accident, my emotional reactions changed, my mental well-being changed, and how I observe the world changed. Again, it is very important to follow up with a patient after initial diagnosis and recovery. Just looking at me from an outside perspective, you would assume that I was an average person. This may be the same way for many others who suffer from TBI, which is why many people are not aware that someone may have it. If more people are taught about the effects and signs, they may know how to interact with someone who suffers from TBI.

Future Implications

I believe the first step in helping TBI patients and families is to expand the research on TBI. Kirk et al. (2015) states that parents and caregivers of children with TBI have unmet informational needs and direction on parenting a child with this condition. My parents were not given many resources on how to parent a child suffering from TBI, so they had to go off of instinct mostly. They had to give me my basic needs of food, water, and shelter but they had to learn certain triggers of emotional reactions and adjust themselves accordingly. My mom said that I had a lot of questions about where my god brother was and why I could not get on the trampoline I had anymore. She had to be very sensitive when telling me that my god brother was with the angels now. She also had to present other things for me to play with so that I would not miss my trampoline or gymnastics class as much. Secondly, experiments with drug based and non-drug-based therapies need to be conducted to see which treatments are most effective in decreasing aggressive behaviors from TBI. Because there is an urgent need for

evidence-based practice guidelines for the full range of mental health consequences of TBI, more health professionals need to advocate for change in policy and treatment of these individuals suffering from TBI.

The next step that needs to happen is creating more support groups. Support groups have been noted as a way to promote the well-being of an individual diagnosed with TBI. I do not know about anyone else, but I love talking out my problems with others. I cannot hold stuff in and let myself explode. I talk to my husband, my friends, and family but none of them can relate to what I am going through because they have not experienced TBI. Powell, Gilson, and Collin (2012) stated that individuals who had been diagnosed with TBI earlier in life were more successful in recovery if they had sought out support from local groups with the aim of growing their spirituality. Effective groups for TBI patients may be located in hospital settings, community agencies, rehabilitation facilities or religious institutions, or even in the home. Wulf-Andersen and Mogensen (2017) suggest that family interventions can have an impact on the victim as well as the family. Instead of taking the victim outside of the home to get cognitive, behavioral, or physical therapy post diagnosis, the family will feel more involved in helping the victim if the therapies were put into the home setting. Although this may cause more stress on the families, it may increase awareness, understanding, and compassion between members of the family while the victim recovers. I really wish this was established when I was discharged from the hospital because I believe it would have given other family members a sense of how to interact with me and help my parents even more during that time. They did not know what TBI was so they could not help as much because of their lack of understanding.

Teachers and educators also need to be aware of TBI and its effects on individuals. None of the teachers in my community knew what TBI was during that time so special instructors had to step in and go into classes with me. They also had to follow an individual service plan to coordinate with how I was given tests, assignments, and away time if I developed a headache. Students who reintegrate into a school following a TBI might act out, be aggressive, or have problems paying attention. I believe that parents, professionals, and teachers need to keep open communication to promote effective treatment plans for young students, especially in terms of behavioral health, for the sake of all students attempting to learn in a single environment. Appropriate plans might give a TBI patient more time on tests, excused absence from class, or other helpful resources, such as regular check-ins with a school counselor.

According to de Kloet et al. (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 dysfunction 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 as seen in my story. Money can be the biggest issue in family dysfunction. Money was a major issue during my recovery because insurance was not enough. Also, being African American was and still is not easy at all in America, but we are taught to be strong no matter what. This is primarily because of our strong roots in spirituality but it is also a cultural aspect. Etowa, Beagan, Eghan, and Bernard (2017) concluded that Black women, in particular, felt that they needed to be made of steel. In other words, their sense of being Black and being a woman gave them the obligation to stand strong no matter what. Black women have to be self-contained and be able to handle anything that comes their way. So even when we suffer from things like depression or anxiety, most will not admit it or go get help because of the cultural aspect of being strong. This needs to stop! There is nothing wrong with seeking help. There is nothing wrong with admitting that there is a problem. 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. 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 family therapists may be called on to provide necessary information and support post diagnosis.

It is important for society to increase awareness of TBI and its effects so that appropriate resources may be allocated for families dealing with a TBI diagnosis. I hope for a program that can connect child patients to their treatment team even after leaving a hospital setting. In my situation, my nurses and doctors were miles away from my hometown. But this is where technology could come into play. Advances in technology like FaceTime could fill in that gap so no one would have to travel far in order to maintain contact. No child should ever feel they have 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 in my later life. Maybe this was because of our location or the business aspect of the medical field. In a business, employees have to do what they need to do and move on to the next task. Sturmberg (2018) suggests that the health care system has left out the “health” portion of care in recent years. Because of the need to get patients out at a faster pace, medical professionals are taught to treat the disease rather than the health of the patient. Health, defined as a personal experiential state, is not the basis of the care the patient receives (Sturmberg, 2018). If you view the definition of health in this aspect, it can be assumed that someone’s health is what they consider good and normal from their personal view. If the patient is not back to their fully functioning self, in their opinion, they are not in good health. This is why I am pushing for change in policy within healthcare for those suffering from TBI. Yes, I understand that doctors and nurses have new patients every day or even every minute but children, in my opinion, need that special bond throughout their life to the people who cared for them during their extended stay away from home. I felt the doctors and nurses who had cared so well for me while I was their patient disappeared from my life when I was discharged. They provided incredible support for me and I felt bonded with many of them. I would have benefitted from furthering a relationship with any of them.

Societally we also find implications for insurance practices. My mother is a teacher in North Carolina, so she receives insurance, which includes mental health and other visits with professionals. I worry about the families who cannot afford insurance. I also worry about the mental health coverage afforded by many insurance providers. Most providers do not afford adequate mental health coverage to their insured. The government should make it even more affordable for victims who have suffered from this condition to get mental counseling.

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 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 significant burden. It is society’s duty, as members of the same community, to lighten the burden of our fellow humans.

Ilie et al. (2015) report that children who suffer from TBI can be burdened from a range of cognitive dysfunction, substance abuse, anxiety, depression, and suicide ideation, 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 anxiety. This point hit hard for me. I cannot tell you how anxiety has pretty much taken over my life. I stress before there is even a reason to stress. I overthink, overanalyze, and overfeel (I know that is not an actual word) everything. They can also suffer from depressive symptoms such as sadness, loss of sleep, and decreased appetites. There are times when I cannot sleep at all no matter how hard I try because my brain will not let me. I

wish it had an on and off switch where I could control it, but it does not work that way. Ryan et al. (2013) suggest that TBI survivors suffer from emotional and communication problems also. Survivors who suffer from communication problems also might experience difficulty maintaining friendships, interviewing for jobs, and developing healthy communication in romantic relationships. I will admit, sometimes I shut completely down and do not know how to communicate my feelings to anyone. I want to tell them that my brain has a million thoughts a minute. I want to tell them that I cannot handle a lot of outside stress at one time because I am already stressed inside my mind. I have anger outbursts at least once a week where I have to scream and call out to God. I have anxiety attacks where I cannot breathe, and I have to rock myself back and forth until I calm down. Many people with TBI may suffer with this just like me. These struggles must be addressed so that TBI patients can live whole and happy lives. Anxiety and depression management (with a mental health professional as opposed to a physician), as well as communication skills should be incorporated into the treatment plan of a person diagnosed with TBI.

One of the main downfalls of autoethnography is failing to consider that confidentiality must still apply in self-narrative (Farrell, Bourgeois-Law, Regehr, & Ajjawi, 2015). In other words, I could not report other's opinions or perspectives unless I had their permission even though it is my story. Autoethnography is based on one's personal experience therefore the researcher has the responsibility to report the truth. Readers must trust their autoethnographic authors to be honest and vulnerable. The goal of research is to inform and help others so researchers, including autoethnographers, have to take the oath that their research is valid and truthful. One limitation to this research is my inability to recall certain events of the accident due to my impaired memory.

Traumatic brain injuries affect many people worldwide every year, can have lifelong effects on patients, and much like most serious medical diagnoses, require extensive strength and resiliency to overcome. This autoethnography has helped me put all the things I feel and experience on a daily basis into words. One of my prayers is for everyone experiencing TBI in some way to have access to all the resources they may need, be those financial, medical, social, or spiritual. Another one of my prayers is for media, child professionals, and researchers to be more concerned with the care and treatment of TBI. I hope for health professionals to establish ways to connect with their pediatric patients following discharge. I hope for the creation of support groups for families experiencing a TBI diagnosis. I hope for insurance companies to expand their mental health coverage. I hope all those who struggle through something horrendous can find purpose in their suffering, much like I found healing and hope after unexplainable loss.

References

- Allen-Collinson, J. (2013). Autoethnography as the engagement of self/other, self/culture, self/politics, selves/futures. In S. Holman Jones, T. E. Adams, & C. Ellis (Eds.), *Handbook of autoethnography* (pp. 281-299). Walnut Creek, CA: Left Coast Press.
- Averett, P. (2009). The search for wonder woman: An autoethnography of feminist identity. *Affilia*, 24(4), 360-368. Retrieved from <https://doi.org/10.1177/0886109909343569>
- Buckley, R. (2015). Autoethnography helps analyse emotions. *Frontiers in Psychology*, 6(209), 1-2. Retrieved from <https://doi.org/10.3389/fpsyg.2015.00209>
- Centers for Disease Control and Prevention (CDC). (2016). *Get the stats on traumatic brain injury in the United States*. Retrieved from https://www.cdc.gov/traumaticbraininjury/get_the_facts.html
- 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. *The Qualitative Report*, 19(37), 1-13. Retrieved from <https://nsuworks.nova.edu/tqr/vol19/iss37/3>.
- 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
- de Kock, W. (2016). Fowler and faithful change. *Scriptura*, 72, 87-95.
- 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.
- Ellis, C. (2004). *The ethnographic I*. Walnut Creek, CA: AltaMira.
- Etowa, J. B., Beagan, B. L., Eghan, F., & Bernard, W. T. (2017). "You feel you have to be made of steel": The strong Black woman, health, and well-being in Nova Scotia. *Health Care for Women International*, 38(4), 379-393.
- 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
- Jones, S. H., Adams, T. E., & Ellis, C. (Eds.). (2016). *Handbook of autoethnography*. New York, NY: Routledge.
- 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
- Kruidenier, R. (2017). Personal encounters with children in an informal settlement: Exploring spirituality. *Verbum et Ecclesia*, 38(1), 1-8.
- Lalonde, G., Bernier, A., Beaudoin, C., Gravel, J., & Beauchamp, M. H. (2018). Investigating social functioning after early mild TBI: The quality of parent-child interactions. *Journal of Neuropsychology*, 12(1), 1-22.
- 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
- 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
- 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., Cassidy, 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
- 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
- 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
- Spina, S., Ziviani, J., & Nixon, J. (2005). Children, brain injury and the resiliency model of family adaptation. *Brain Impairment*, 6(1), 33-44.
- Sturmberg, J. P. (2018). Putting health back into the healthcare system. In J. P. Sturmberg (Ed.), *Putting systems and complexity sciences into practice: Sharing the experience* (pp. 1-8). Cham, Switzerland: Springer.
- Taylor, C. A., Bell, J. M., Breiding, M. J., & Xu, L. (2017). Traumatic brain injury-related emergency department visits, hospitalizations, and deaths-United States, 2007 and 2013. *Morbidity and mortality weekly report. Surveillance summaries*, 66(9), 1-16. doi:10.15585/mmwr.ss6609a1
- Wulf-Andersen, C., & Mogensen, J. (2017). Family and home in cognitive rehabilitation after brain injury: The importance of family oriented interventions. *NeuroRehabilitation*, 41(2), 519-525.

Author Note

Quanisha Miffin (Maiden name: Davis), is originally from Elizabeth City, NC. She received her Bachelor's (2013) and Master's Degree (2016) at East Carolina University in Greenville, NC. She is now living in Virginia as a wife and stay at home mom to her son. Her interests include early intervention and resiliency after a diagnosis. She believes that strong faith (internal factor) and a supportive atmosphere (external factor) are the keys to successful recovery after a crisis situation/ disability. Correspondence regarding this article can be addressed directly to: davisq09@students.ecu.edu.

Archana V. Hegde, PhD BK is an Associate Professor in the Department of Human Development and Family Science. Her primary area of research is conducted using mixed methods, on topics related to early childhood teacher education and diversity. Dr Hegde chaired

the research study and was part of the student's journey that was conducted utilizing autoethnography. Correspondence regarding this article can also be addressed directly to: hegdea@ecu.edu or reach her office calling (252) 328 5712

Paige Averett, PhD, MSW, is a Professor and Director of Graduate Programs in the School of Social Work at East Carolina University. She is a qualitative methodologist and finds value in stories, and the thick, rich detail found in qualitative methods, particularly those found in autoethnography. Correspondence regarding this article can also be addressed directly to: averettp@ecu.edu.

Natalia Sira, PhD, MD, is an associate professor in the Department of Human Development and Family Science at East Carolina University. She is teaching undergraduate and graduate courses in child life, human development and early interventions. Natalia is convinced that human functioning, health and behavior are best explained from a holistic and systemic approach. taking into consideration a variety of equally important factors such as family relationships and lifestyle, diet, exercise and social and cultural influences. Her research interests include health and coping, resilience and spirituality, attachment relationships and health outcomes. Correspondence regarding this article can also be addressed directly to: siran@ecu.edu.

Rae Holliday, LMFT received her Bachelor of Arts in Philosophy from Wake Forest University (2016) and her Master's of Science in Marriage and Family Therapy from East Carolina University (2018). Currently Rae works as a Behavioral Health Therapist at Nationwide Children's Hospital in Columbus, Ohio on the Acute Psychiatric Unit.

Quanisha would personally like to thank God for making all things possible. She would like to dedicate this to her son, Khalil Miffin. "Mommy loves you so much!" She would like to thank her husband, Charles Miffin, and her family (especially her mom, Sherrie Spellman, her stepdad, Darnell Spellman and her dad, Milford Creecy) for their support, insight, and challenging her to be the best that she can be. She wants to send a huge acknowledgement to her team of excellent professors who pushed her beyond what she thought was possible. Dr. Hegde, Dr. Averett, and Dr. Sira, thank you so much for your guidance and encouragement through this process. Quanisha also wants to say, "Thank you Rachael Holiday for your insight into correcting and expanding ideas. Rest in peace Grandma ReeRee, keep smiling down on me."

Copyright 2019: Quanisha Miffin, Archana V. Hedge, Paige Averett, Natalia Sira, Rachael Holiday, and Nova Southeastern University.

Article Citation

Miffin, Q., Hedge, A. V., Averett, P., Sira, N., & Holiday, R. (2019). From test to testimony: Resiliency after a TBI diagnosis. *The Qualitative Report*, 24(3), 513-531. Retrieved from <https://nsuworks.nova.edu/tqr/vol24/iss3/6>
