1-1-2017

Engaging the Brave and the Bold: Exploring the Discourses of Disability Through Life Stories

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Stories

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A Dissertation

Presented to

the Faculty of Social Sciences

University of Denver

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In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

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by

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August 2017

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Title: Engaging the Brave and the Bold: Exploring the Discourses of Disability Through Life Stories
Advisor: Dr. Elizabeth Suter
Degree Date: August 2017

ABSTRACT

Understanding the meaning making of having an acquired physical disability still remains a mystery today. With more than 20 percent of our total population experiencing some form of disability, this study explores discourses of disability that emerge from participants' life stories. This study interviewed 20 participants using a modified version of McAdams' (1993) Life Story Interview Protocol. Utilizing Relational Dialectics Theory and a thematic discourse analysis, two primary discourses emerged from participant talk. (1) the biomedical discourse of disability and (2) the disability discourse of normalcy. The latter discourse can be broken down even further into (1) the sociolinguistic discourse of disability and (2) the biopolitical discourse of disability.

Called forth through language, these discourses provide a site of analysis to better understand the sense-making that persons with acquired physical disabilities experience as they try and understand what it means to have a disability. From these two discourses, an analysis of language choice sheds insight into meaning-making, while providing unique insight into researching this community.

ACKNOWLEDGEMENTS

To my mentors: Beth, thank you for not giving up on me and for listening to Dr. Braithwaite all those years ago in giving me a chance. Roy, thank you for your patience, your guidance and introducing me to Levinas. Scott, thank you for believing in me and setting me onto this path 15 years ago.

To my boys in the Nectar: I love you guys. You have made my experience in Denver amazing, even with all of the headache, heartaches and stress. To my academic family: Leah, thank you for the late night dinners, and all of the work we collaborated on. Lacey, thank you for reminding me to relax and for always having a cigarette or a lighter. Steph, thank you for the late night rap sessions in the street. Salma, thank you for the weekly coffees, and being willing in letting me ask you an endless series of questions #hirabi. To Lee: Thank you for understanding just how hard this process has been, for giving me the time to work and listening as I vented about this whole process.

To my parents: Thank you for supporting us when times got hard. From the work on our house, the financial support and checking in regularly, this journey took a long time and without you, we could never have been able to do all of this. I love you.

To my wife: Thank you for agreeing 11 years ago to embark on this journey with me. We have lived in three states and have had four homes. We have earned five degrees, have had seven jobs, we have two pets and are raising 4 wonderful children. No matter where I go, you are my home. Know that I love you, even if I don't tell you that enough.

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CHAPTER ONE: INTRODUCTION

In 2002, the population of people with severe physical disabilities was approximately thirty-five million (US Census, 2004). On August 20th of the same year, at 4:36 am, that number grew by one. For all intents and purposes, my story prior to this moment was pretty typical. I grew up in a mostly homogeneous community consisting of middle class, Christian White people. I graduated from high school a varsity athlete, musician and avid "gamer." I dated the same woman throughout my senior year and the two of us went off to college together. After completing my first year of college, I chose to take a summer job selling books door to door. After a long and grueling summer of long hours, countless rejection and a little money, I was headed home with other students to start college. This is where my story starts.

The drive was supposed to take us somewhere between 18 and 22 hours. We had to estimate the travel time, as our GPS consisted of a stack of raggedy state road maps, and a four-month old printout that was sun faded and covered in coffee stains. The group I was travelling with consisted of three other people that I did not know very well. The interactions that I had with these people prior to travelling with them tended to consist of quick greetings and small talk during our weekly division meetings

We left Houston in the late afternoon. Our goal was to make Nashville by the following evening and we knew that we had to drive long shifts in order to make it there

on time. There were two cars in our caravan, a 1998 Dodge Intrepid and a 1996 Buick Town car. Upon a quick conversation amongst us, I chose to drive the first shift in the Buick. The air conditioning in the Buick worked better and I did not want to drive a long distance while sitting in my own sweat.

The driving was long and quite uneventful. My passenger went to sleep almost immediately and after nine hours, my exhaustion was taking over. The group decided to stop in New Orleans for a short break, refuel and switch drivers. I remember being excited by this, as one of my goals on a bucket list that I wrote for my freshmen seminar course was to walk Bourbon Street. Little did I know that this was going to be the last time that I would actually get to physically walk anywhere.

We parked the cars in a Marathon gas station parking lot on Royale Street. The parking lot neighbored Bourbon Street and was a great place to leave our vehicles. After spending a few hours eating, rehydrating and stretching our legs, all the while exploring the still bustling French quarter, we climbed back into the cars and prepared to continue our journey. I chose to lay down in the backseat of one of the cars as I had already driven my shift. One of the people in our group, a young woman that I had only met a couple of times, but never really had a conversation with, chose to drive our vehicle. We made small talk as we looked over the map. The next leg of our journey was to take us out of Louisiana and through the state of Mississippi.

The driver pulled the car out of park and we headed out of the parking lot of the gas station. I closed my eyes as sleep began to claw at me. I did not fight the sleep as I knew we had another 10-12 hours left of driving and I needed to sleep a bit before I had

to drive again. I imagine the weight of sleep had its hold on me before we even got out of the French Quarter.

My memories after this point are a bit disjointed. The next memory I have is waking up to someone pushing me back down into the mud. I was disoriented and the pungent aroma of swamp burned my nose. Rough hands held me down and gently told me to stay still. His calming words contradicted the roughness of his hands and I went back to sleep. My next memory was the feeling of falling forward. I later learned that I was being carried out of a ravine by a team of emergency responders.

After this, I awoke as doctors were cutting off my clothing and breaking the threads of the jewelry in my newly pierced nipples. I remember the bright lights of the emergency room and the masked faces frantically moving around me. The pain of the doctors removing the jewelry quickly faded as the sea of bodies tending to me became overwhelming. Disoriented, I asked one of the many masked doctors', "Am I going to die?" He looked down blankly and said, "I don't know."

My ability to comprehend the situation came into context as another doctor asked me to wiggle my toes. I insisted that I was, as he repeated the question over and over. Finally, before his words hit me, his frown gave way to the reality of my situation. I was not moving my toes. I quickly faded back into the darkness.

The next memory that I have is of being jolted awake and quickly falling back asleep. I learned later that the jolt was my body being lifted into the helicopter, but I am not sure if it was the first flight for life trip, or the second. It was later explained to me

that each hospital that I arrived at did not know how to treat my injuries. My next memory comes from that evening.

It was about 10:30 at night and I was in the intensive care unit. I awoke in a hospital bed to the sound of a large crash. The beeping and buzzing of machines were drowned out by an argument and a violent physical confrontation between two men. I recognized the sound of my father's voice yelling at another man and the confrontation revealed itself when the orderly threatened to call security on him. A quick shove and the smaller man went tumbling to the floor as my father and mother entered the room. Clearly, visiting hours did not prevent a set of parents from seeing their child.

Consciousness quickly fled my body as the fentanyl drip that I was attached to pumped more sleep into my body. I awoke the next day, or maybe the day after, I am still not sure which, with someone holding my hand. I opened my eyes and found my girlfriend (who would later become my wife) sitting next to me. As I scanned the small hospital room, I spotted my older brother sleeping in a chair and my mother sitting on the couch. My father was watching over me as he stood in the corner of the room, his tall frame leaning on the radiator that was adjacent to the window. As I started to really wake up, my girlfriend sat up and my father approached the bed. I asked what had happened, and they were able to explain to me where I was and what had happened. The driver of our car had fallen asleep at the wheel. The police reported that she had lost control of the vehicle while traveling at high speeds. Our car had left the road and proceeded down into a ravine where the vehicle struck a tree travelling at speeds in excess of 70 MPH. I was

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ejected from the vehicle and was found over a 100 yards away. The driver of the vehicle also had suffered severe injuries and was being cared for in a different hospital.

My parents informed me that after my accident, I had been transported and transferred through three different hospitals before arriving at the University Hospital, a level one trauma center designed to help patients like me. My parents were notified by one of the members of my group at 10:30am on the same morning of my accident. They immediately headed to the airport and bought tickets to the city that I was originally being airlifted to. Their flight was scheduled for early afternoon. What they did not know was the plan that the hospital had in moving me to another hospital. Approximately half-way through their flight, around 3:30pm, the hospital notified the airline that I was being moved to another hospital on the other side of the state and the plane made an unexpected detour so that my parents could get off and board a different flight to the city that I was being transferred to.

While my parents shared with me what had happened, a group of doctors and nurses entered the room. The lead doctor had a stack of x-rays in hand and a solemn look on his face. He introduced himself and began to retell me the events of the night. He explained that I had suffered a severe spinal subluxation, which was a result of hitting the ground after being ejected from the vehicle. Upon completing x-rays, they found that I had not broken any bones, but due to the flexing of my spinal cord, approximately two inches of the actual cord had become severely bruised. As he told this story, I watched my family. Tears swelled in my father's eyes and ran freely from my mother's. My brother's eyes were locked on the ground and my girlfriend quietly watched me. Her

vibrantly blue eyes were welling with tears. As the doctor's coldly technical explanation completed, he told me that I would have "less than five percent of a five percent chance" of ever using my legs again. It took me awhile to understand what he meant by this. Did he mean that I still had a slim chance? For a moment, my mind raced with possibilities and hope and I know that he saw this on my face. I asked him to explain this, and with a frown told me that there was virtually no chance that my spine would heal itself.

After receiving this news, I asked him how this would affect my ability to have children. His surprise to my question did not escape me, but he did not have an answer. Tears swelled in my own eyes, as the future of my life immediately became uncertain. It is a strange thought for me to try and explain to someone what it is like to not be able to feel my lower abdomen, legs or feet, yet what I could not wrap my mind around was what I was going to do next. What was my recovery process going to be like? How would my actual life change? What burden would I be on those that I loved? That evening, when my parents and brother were getting food from the cafeteria, and I decided to talk to my girlfriend about this. As happy as I was to have her there, I was concerned more for how my injury and new state of life would impact our relationship. I gave her an out and told her that I would not blame her for leaving. I explained that my life had just become instantly more challenging and if she did not want to have to deal with this change, I would understand. After a brief pause, she smiled and her piercing blue eyes caught mine. In that moment, I realized that I had looked away from her while speaking. Her response surprised me as she told me that although she did not know what the future

would look like, she had no plans of finding out without me. Tears welled up in my eyes as I smiled.

A few days later, my parents arranged for me to be airlifted again to the Mayo clinic in Minnesota. I spent a total of 10 days in the initial hospital. By the end of my stay, I was starting to get really sick. I was constantly nauseous, my body began to ache all over and my stomach was turning very black in color and was very distended. I could tell something was wrong, and each time I asked about my symptoms, I was told that my experiences were common to people who have had severe trauma. When they told me that I was leaving, I was very grateful. My parents chartered a private medical jet to transfer me from the University Hospital in Jackson, Mississippi to the Mayo Clinic in Rochester, Minnesota. The flight was aboard a small two engine airplane and the passengers consisted of two nurses, the pilot and myself.

During the four-hour flight, the nursing staff noted that my temperature was fluctuating badly and that my stomach was very rigid. By the time the flight landed, my temperature had risen from 97.4° to 104.1° and they were concerned that I might have internal injuries that had gone untreated during my stay in Mississippi. They notified the Mayo Clinic of the changes in my condition and I was transported from the airfield to the hospital via ambulance. Upon arriving, I was immediately brought to the radiology department where I received a cat scan. The results confirmed the suspicions of the nursing staff that travelled with me. I had ruptured my colon and for 10 days I had bile leaking into my abdomen. At this point, I was in the initial stages of septicemia, a very

deadly infection that spreads quickly, and they needed to put me into emergency surgery to assess the damage that the infection had already done to my body.

Originally planned to take 45 minutes, the doctors had me in surgery for over four and a half. The infection was far worse than they expected and they had to clean out all of the bile that had slowly been filling my abdominal cavity. I awoke in the middle of the night. I had a nasal-gastro tube protruding from my nose and I could feel the smooth plastic in the back of my throat. I moved my hand to my stomach and found a line of ridges from the row of steel staples that now ran from my sternum to my pubic bone. The bandage covering the staples caught the rough scabs on my hands as I ran my fingers over it. At this point, my initial cuts, scrapes and bruises were almost healed. My arms were still scarred and the doctors were certain that some of these wounds still contained remnants of glass from where I went through the windshield.

A monitor faced me and the flashing illuminated numbers made little sense. In my hand was a small button that I noticed attached to the side of the monitor. After studying the device, I noticed two containers also attached on the side of the screen. One read, "morphine" and the other "fentanyl." The button in my hand dispensed these drugs through an IV, which I later learned were for managing pain and alertness. In my other arm was another IV, this connected to a series of bags hanging above me, it was dark and I was not certain what was in them.

I spent a total of two weeks in intensive care. During this time, it was explained to me that after the doctors were satisfied that I was stable enough, they would transfer me from the intensive care unit to the rehabilitation unit and from there, would perform

another surgery fusing my spine with titanium rods. This would be done so that I would have trunk stability as my abdomen and lower back muscles no longer functioned as they should. After this, I would spend approximately 30 days re-learning basic life skills, be fitted for my first wheelchair and learn what I need to learn to regain some semblance of independence before being released back into the world.

Unfortunately, another hurdle presented itself. On my 20th birthday, after being transferred to the rehabilitation wing, just days prior to my scheduled spinal fusion, the wound from the emergency surgery that was healing on my stomach had reopened and become infected.

I remember this day very well. Friends from college had made plans to take the hour long drive to come visit me and they were bringing me a delicious looking birthday cake, or at least that is how it was described to me. However, that morning, a member of the nursing staff noticed a putrid green slime oozing from the staples and quarantined me to the room. As this processed happened fairly quickly, I was unable to notify my friends who were already en route to the hospital. Upon arriving, they were informed that they would have to wait while doctors decided what to do next.

Hours passed as the doctors deliberated amongst each other. A member of the Minnesota CDC and resident infectious disease doctor came to my room and examined the staples. Her frown was not promising and after a few minutes she left the room. I waited for what seemed like hours as I spoke with my friends on the telephone. My parents had also recently arrived and they were visiting with each other in the waiting area. Late in the afternoon, a team of doctors and the woman from the CDC re-entered

my room. With them came a member of a different nursing staff who was pushing a metal cart full of what looked like surgical instruments.

The CDC doctor explained that they had to reopen and debride the wound, which meant they were going to remove all the staples, pull open the wound and scrub the inside of it with a metal brush. Upon completion, they would then leave the wound and exposed so that it may heal on its own.

The process of them removing the staples was incredibly painful. A doctor began by clipping the center of each staple with a wire cutter. Then, using a pair of industrial sized tweezers, plucked each end out of my skin. After the nurse completed the removal of the staples, she informed me that the next part would probably hurt. She was right. A steel brush was used to scrape and scrub the inside of the skin that covered my abdomen. After a few minutes, the nurse took a solution of saline and an anti-bacterial agent and immersed a long piece of gauze into it. She removed the gauze from the solution and packed it into the newly debrided wound and covered the site with another piece of gauze. Her uneasy smile told me that she was done and I remember feeling relieved.

After she left, my parents and my girlfriend (who would later become my wife) entered the room. They seemed happy to see that the procedure was complete and asked me to explain what had happened. After a brief explanation on my part, they wished me happy birthday. We laughed at the thought that my birthday present was the debridement of the wound on my stomach. I asked them if my friends were still there, and they informed me that they were not. They had to head back to college and wanted me to

know that they would try and come back again soon. I then asked about the delicious birthday cake, and sadly there was none left. I was sad.

The complication to my stomach changed an initial 30 day plan into one that spanned three and a half months. During this time, I learned a lot about how my body had changed. I had lost over 80 lbs and my body, specifically my legs, had become a lot smaller. They fitted me for my first wheelchair while lying in a hospital bed and fitted me for a Thoracolumbosacral orthosis (TLSO) brace. The purpose of the brace was to provide for me trunk support as my back learned to compensate for my lack of muscle control. After a month and a half, I was finally allowed to sit for the first time and I got to try out my new wheelchair. This transition was a lot harder than I expected. I learned that my blood pressure was not being managed appropriately and I became instantly dizzy and nauseous. However, after a series of attempts that became longer and longer, I was finally able to sit on my own without becoming sick. Over the next two months, I relearned skills that I had previously taken for granted. From getting dressed to using the bathroom, I had to learn how to accomplish these tasks from a sitting position. During this time, I also met and interacted with a population of people that I had never really encountered, a population that I was now a part of. I was meeting other people with acquired physical disabilities and I realized just how little I knew about the lives of people with physical disabilities.

As ashamed as I am to admit this, until this point, I always carried a level of sadness and pity when I saw people in wheelchairs, or with prosthetic limbs, using canes, crutches or using hearing aids. My own aunt had been in a serious car accident a few

years prior and was left without the ability to use her arms or her legs, her quadriplegia saddened me and I remember telling my father that I was not comfortable visiting her, or seeing her as she was now. I claimed that I wanted to remember her for who she was prior to her accident. Later, I would learn how hurtful this sentiment can be to receive.

My own accident and three and a half months' worth of rehabilitation had already irrevocably changed my perception of what it meant to live with a disability. In this short amount of time, I learned how not to look toward other people with sympathy. As I learned new skills in my rehabilitation, my independence grew, and so with it, my understanding in just how marginalized this [my] community was. During the month of October and the beginning of November, I learned that once I was in my chair, I was allowed to leave the hospital for hours at a time. Most days, I would take the clinic shuttle from the hospital that I was in to the main shopping area downtown and from there, either *walk* over to the mall adjacent or visit a used book store that was located across the street. As I would travel to various locations around town, it became increasingly clear how people viewed my body. I could not help but notice their sad looks towards me as I would slowly push and struggle with tasks like opening doors, or travelling uphill. Sometimes, people would approach me to offer me assistance, while others would dart ahead to hold open doors. These acts reinforced my disabled identity and really put into perspective what I had lost. I remember having conversations with my girlfriend at the time on how I felt when people would look at me sadly. I told her that I did not really notice, but I did. I think as a mechanism of trying to protect my positive

attitude, I forced myself to not think about how much it hurt for people to look at me with sadness and pity.

In total, I spent three and a half months in four separate hospitals. I followed that with eight weeks of outpatient rehabilitation, while living with my parents. That winter, the student life office at the University of Wisconsin, La Crosse contacted me to let me know that if I wanted to return back to school and live on campus, I would have to move into a different dormitory, as the one that I was supposed to live in, was not accessible. As unhappy as I was about this decision, I reluctantly agreed and moved back to college. Upon arriving, I was accosted with a new reality. The close friends that I had made from the year before were no longer as interested in hanging out as much and as a result, those friendships quickly deteriorated. I had one friend that used my own line against me. He told me one evening that he did not want to see me as I am, but rather remember me for who I was. My wheelchair freaked him out and he did not know how to interact with me anymore. Those words hurt. Was I a monster?

For some of the friends that I had made the year prior in college, I could not help but see the differing levels of sadness and pity they had for me as I struggled to acclimate to college life. At the time, I could not keep those relationships going. The pain of their gazes hurt more than any of the injuries that I had sustained. In the end, I would argue that I kept about five friends from my life prior to acquiring my disability, and that winter I decided to start making new friends and decide in which direction I wanted my life to head. Thankfully, the University's decision to move me into the "accessible" dorm effectively introduced me to someone who would not only become one of my closest

friends but who would also act as a mentor to me in the world of having a disability. On my first night in the hall, my neighbor asked if I had met the other "guy in a chair." I told him that I had not, and he described him as a little guy with small legs. He could not tell me his name. I asked around and it seemed that people saw him come and go, but nobody knew what his name was, or where he was from. To them, he was a ghost.

That night, I was filling up my water bottle at the drinking fountain outside in the hallway. It was around 12:30am and I looked up as I heard the lobby door open. I saw the man that I described earlier. He was considerably shorter than me, he sat in a rigid framed white wheelchair and he had on a black and green Adidas jacket and Nike hat. He did have little legs that were not hidden behind a pair of black corduroys. As he pushed down the hallway, we made eye contact and exchanged greetings. We checked each other out as we made small talk. He introduced himself as Bill and told me he was a therapeutic recreation major. He was from just outside of Wisconsin Dells and was an avid wheelchair basketball player. He explained that he did not really know anyone else on campus and spent every weekend going back to his mother's house to see his girlfriend, who still happened to be in high school. Our small talk became a conversation as I invited him into my dorm room to hang out. At this point, I did not have a typical dorm room. There was only one accessible dorm room on the entire campus and that was Bill's. The accommodations were not really all that different than a traditional dorm room, except he had an attached bathroom and a lower closet hanger. After agreeing to move dormitories,

I was placed into the 1st floor study, a 44-foot-long, 20 foot deep room with a bay of windows that overlooked a courtyard. There were two standard sized beds and I had furnished the room with two couches, two televisions and 14 car speakers that were wired through a VCR. For a college dorm room, it was cozy. We stayed up the rest of that night and part of the following morning sharing stories and getting to know each other. During this time, I realized that Bill was not shy, he did however lack some of the necessary social skills to build relationships with the other people who lived in our dorm. Up until this point, all of his friends were other people with physical disabilities and he did not know how to interact and bond with able-bodied people, specifically men.

Over the coming weeks, our relationship grew. I introduced him to my friends in marching band, and some of the other people who lived on our floor. We played video games, smoked cigarettes and he sang, while I played guitar. He taught me the value in not saying, "I can't," taught me wheelchair basketball and introduced me to other people with physical disabilities. We quickly became inseparable and in the process, built a pretty strong group of friends from very diverse communities. For the first time since my accident, I felt like I was finally starting to fit in.

My classes restarted and my education continued as I majored and minored in Communication Studies. Unlike most students, I felt that I had multiple advisors and mentors during this process. As I approached the upper level courses, my advisor and one of my mentor's introduced me to work that was conducted by his advisor, Dr. Dawn Braithwaite. I consumed the articles that he assigned over the course of a few days and during this process, I frantically scribbled notes and thoughts, responses and critiques of

the research. One afternoon, in an embarrassingly arrogant fashion, I stormed into his office and threw down the articles in frustration. Although I was able to relate to what the research found, I exclaimed how the interpretations were not quite accurate. People with disabilities did not all see the world in the ways presented in these articles. Not everyone was afraid or timid, nor did everyone lack the ability to be competent in communicating their needs. I was frustrated, and as I reflect upon that afternoon, I was also very naïve.

Through his infinite patience, my advisor allowed me to finish my rant. Once I was done, he smiled and told me that I was right. Or at least, I was sort of correct in what I was recognizing. Up until this point, I had not been introduced to the different paradigms of research and the types of research questions that underpinned them. He went on to explain that Dr. Braithwaite would probably agree that not all people with physical disabilities would see the world as they were presented within these articles. She would probably also point out just how little we actually knew about this community. My advisor suggested that I read a book that Dr. Braithwaite and Dr. Thompson edited in 2000. This text collected various communication-based research surrounding people with disabilities. The book was meant to give me a broader understanding of what communication scholars did know about the community as well as to illuminate just how much was left to learn. This conversation ended with his suggestion that I could someday be one of the people who helped fill these gaps in knowledge. I could create an entire program of research, a career that would work towards filling the gaps that I recognized in those readings. This conversation, which occurred in a small academic office in 2004

was the first step in what has turned into be a 13-year long journey of personal and professional growth.

Throughout my academic career, I have worked towards filling these gaps. I have studied various issues surrounding people with physical disabilities, their relationships, their identity and have even turned the lens upon myself. From accommodations within the college classroom to relational sense-making, I have read, written and interviewed people about what it is like to have a physical disability. I have examined my own relationships with my partner, my children and my friends and explored what having a disability means in the context of being male, a father and a friend.

Over these past 13 years, I have learned a lot about how people with physical disabilities talk about having a disability. Their experiences have echoed a claim made by Margaret Shildrick (2002) that, "no disability is the same," and each unique experience builds towards the uniqueness of this community. Researchers within the social sciences have explored the experiences of the individual (Darling, 2013), their relationships with able-bodied individuals (Braithwaite & Harter, 2000; Soule & Roloff, 2000), family members and caregivers (Harrigan, 2009), and romantic relationships (Nemeth, 2000).

Other disability-based research has explored how people with physical disabilities organizational settings such as the workplace (Bruyere, Etickson, & Van Looy, 2005) and the college classroom (Sachs & Schreuer, 2011; Worley, 2000), while some social scientists have explored the use of technology in the use of social support (Braithwaite &

Eckstein, 1997), assistive aids (Seelman, 2005), and computer mediated communication (Green, Brightman, & Kassner, 2012; Fox, 2000).

Although not exhaustive, this body of research illustrates how we understand what disability means. The body of research informs the larger meaning which Baxter (2011) labels as a discourse, or system of meaning. Using the above example, each piece of research situates a physical disability as meaning something particular to the individual(s) being studied. These examples, their lived experiences, inform how meaning is made in regards to having a physical disability.

In her book, *Voicing Relationships,* Baxter articulates the definition of a discourse by using an example of an apple. Depending on what are past cultural and relational experiences, the context of the current moment, or our individual relationship with the communication partner, the apple might carry a different meaning. Within the same vein, having a disability means something different to each person and is consistently being informed by past experiences, cultural scripts, individual relationships with others and the context of the moment. Baxter labels this meaning making as being located on the utterance chain, a concept based on Bakhtin's notion of a multivocalic moment in which multiple relational and cultural discourses are in competition with each other and the interpenetration of these discourses create meaning (Baxter, 2011).

This study focuses on exploring how discourses animate the meaning of disability for persons with newly acquired physical disabilities. The study is framed in the newest articulation of Relational Dialectics, "a theory of relational meaning making – that is, how the meanings surrounding individual relationship identities are constructed through language use" (Baxter, 2011, p. 2). For Baxter, "meaning making happens in the

utterance chain – the "chain of speech communication" (p. 50). Baxter (2011) explains that within the utterance chain, discourses come together in one of four primary forms: distal already-spoken, distal not-yet-spoken, proximal already-spoken, and proximal not-yet-spoken. She further explains that the distal versus proximal refers to the temporal proximity of prior and anticipated utterances are to the immediate utterance. This can be situated by understanding larger cultural or societal experiences being distal in nature, while relational discourses are more proximal in nature. It is important to note that for this study, the data collected is positioned on the distal, already spoken link of an utterance chain, which relates to how cultural voices permeate relational meaning-making within the moment (Baxter, 2011, p. 50).

The theory also illustrates the difference in power between discourses, where some discourses are privileged (centripetal) within society, or within specific relationships, while others are marginalized (centrifugal) within the same contexts. These discourses struggle against each other in an attempt to become centered. In the context of having a physical disability, this attribute is marginalized and often positioned in a negative relationship with being able-bodied or *normal*. This apparent separation is reinforced through everyday talk, societal and legal precedents, physical representations in the media and medical discourses and advice. In the United States, having a physical disability is viewed negatively both at a systematic and interpersonal level. There is also a level of uncertainty that exists between the able-bodied community and the disabled community. Although this may seem problematic, it actually illustrates just how diverse this population is in terms of experiences.

This study focuses specifically on people with newly acquired physical disabilities. This population are currently transitioning through a ruptured identity, one in which they were able-bodied to now being disabled. This transitional point of rupture represents a dialogically expansive moment in which discourses of ability or normalcy and disability are at play. For this study, adults are to be interviewed who have acquired a disability within the past three years, and have completed all of their intended rehabilitation. This specific population are still transitioning and negotiating their identities, their communicative strategies and their social worlds when faced with trying to understand what it means to have a physical disability.

To explore this phenomenon, this study will collect data through the use of an adapted version of McAdams (1993; 2006) life story interview protocol. This data collection method solicits stories from an individual that will explore different portions of their lives and inevitably see how their past experiences and future expectations affect their view of their socially constructed world. Baxter (2011) situates the importance of narrative as it can place different voices in play simultaneously. Raggat (2006) also positions the uniqueness of a dialogical lens on narratives and life stories. In his article, Raggat positions the difficulty in trying to capture the meanings behind an individual's perspective of the world through traditional narrative approaches. Situating questions that challenge the wholeness and complexity of each individual, the author positioned a dialogical framework that addresses narratives as a conversation between internal narrators. In essence, the fact that individuals choose certain stories, and not others display an inherent internal conversation in which certain discourses emerge as important and vital for understanding the storyteller's position. This decision is influenced by past

experiences, cultural scripts and as Bakhtin (1986) argues the anticipated responses from the storyteller's immediate audience (addressee) and potential audiences (superaddressees).

To analyze this data, a thematic discourse analysis will be employed to uncover the discourses that are voiced within each story and how these discourses animate meaning of disability for persons with newly acquired physical disabilities. Baxter identifies stories (narratives) as a dialogically expansive type of data, rich with a multitude of cultural and relational voices (discourses) that interpenetrate within the moment to create meaning. Baxter argues that choosing stories as the site for exploring the interplay of discourses is extremely poignant as people are exceptionally good at putting multiple viewpoints into play simultaneously (Baxter, 2011). This idea, also known as multivocalics, allows for meaning to emerge from the language participants choose to use to tell their stories.

The results and conclusions drawn from this study provide significant academic and rehabilitative value by discursively approaching research on persons with newly acquired physical disabilities. By exploring the process of meaning making of having a disability amongst persons with newly acquired physical disabilities, a foundational structure of understanding may be formed. Fundamentally, this project analyzes how power is invoked through the stories of the participants and actively explores privileged and marginalized discourses of disability that are engaged in dialogue. By studying people with newly acquired physical disability provides a unique insight into the messages, experiences and interactions that help shape their world view. By focusing on this point of rupture, we are provided insight into the interplay between competing

discourses as a person discursively works through the transition of being able-bodied to being disabled. The results of this project will not only create a foundational structure on understanding the discourse(s) of disability, but create groundwork for future research on understanding the communicative strategies, experiences and lives of persons with acquired physical disabilities. This information can then be employed not only by academic researchers, but medical and rehabilitation specialists when designing plans to help assist in the transition for future members of this community.

CHAPTER TWO: METHOD

Acquiring a physical disability "is a major disruption to one's biography. When the body is assaulted . . . one's sense of wholeness, on which a sense of order rides, disintegrates. One must reconstitute that sense of wholeness in order to regain a sense of continuity" (Becker, 1999, p. 42). In the United States, there are 56 million Americans with a disability, with two-thirds of this number having a severe physical disability (Brault, 2012). With such a significant potion of our population living with a severe physical disability, scholars have begun to study the various contextual and relational phenomenon that relate to the population of persons with physical disabilities within the United States.

Research in Communication Studies involving disabilities is disparate with a small number of scholars focusing their efforts toward exploring the phenomenon of disability. Prior to the 1980s, disability research, specifically research surrounding physical disabilities positioned individuals as need dependent upon able-bodied individuals. Not much was known about how individuals with disabilities communicated, nor did we understand much about how they interacted with others, how they were portrayed in popular culture and was written primarily from the perspective of able-bodied individuals (Thompson & Braithwaite, 2000).

For interpersonal and identity scholars, disability is socially constructed as a defining characteristic for an individual (Braithwaite & Thompson, 2000). Historically, research on persons with physical disabilities was framed within a model of social deviancy, establishing that persons with physical disabilities were often viewed as not only different from the majority of the population (Braithwaite, 1988; 1990), but viewed as lesser by the majority as well (Lindemann, 2010). The framework for social deviancy emerged from the work of Goffman (1958; 1963) which situated and explained the role of stigma within society and articulated that a person may have unwanted or undesirable identities ascribed to them based on a variety of observable and unobservable characteristics.

While the study of people with physical disabilities has increased steadily in other disciplines, the field of Communication Studies, specifically within Interpersonal Communication still remains spare. A large amount of the early work within our field was initially conducted in the 1990's. During this time, an interpersonal and family scholar, Dawn Braithwaite with various colleagues began to study a population of people with physical disabilities. To begin, Braithwaite (1990) started this research by exploring the cultural impacts of transitioning between able-bodied to disabled. In 1991, Dr. Braithwaite explored privacy management strategies. Three years later, Braithwaite and Labrecque (1994) utilized an application based approach by exploring the connection between the Americans with Disability Act (ADA) and interpersonal research and training. In 1999, Braithwaite, Waldron and Finn researched the role of computer-mediated communication and social support groups for persons with disabilities. In 2000,

Thompson and Braithwaite published a seminal handbook collecting a variety of disability-based communication research that 17 years later, still stands as canonical for disability scholars. In 2003, Braithwaite and Eckstein started to conceptualize how assistance is managed communicatively by persons with disabilities.

Throughout all of this research, disability began to shift away from a traditional construction of disability, one that is founded in a model of social deviance. Historically, persons with disabilities were painted negatively. Since then, a variety of methodological and theoretical approaches have sought to shed more light onto this population and in many cases, act as resistance to the misunderstandings surrounding this community.

This project was forced to employ research outside of Communication Studies. One perspective that lends support to this project, draws research from the medical and rehabilitative sciences. Additionally, research is also drawn from Psychology, Sociology and other related social sciences.

By framing the extant research surrounding this community through the lens of social deviancy and health, questions of culture quickly arise. The questions of culture, are discursive in nature, as how people talk, tell stories and share with each other are influenced by how they view the world. They also ask us to evaluate what is normal, different and lesser. How are these ideas communicated throughout the various communities? (Braithwaite, 1990).

One concept,

Rational determinism, a dominant cultural ethos in the United States, shapes cultural discourses on normalcy (ableness) . . . These discourses . . . are all moral discourses. That is, they reflect dominant ideologies about how life should be lived. (Murphy et al., 1988, p. 16-17).

The discourse of normalcy is positively positioned against the discourse of disability, and shape the cultural expectations that exist between people with physical disabilities and their able-bodied relational partners. The argument of normalcy is a resistive construction that challenges pre-conceived ideas that ability and disability are binary.

This review of literature will begin by contextualizing the extant research in the fields of Communication Studies, Anthropology, Sociology, Rehabilitative Medicine, Disability Studies, Education and Behavioral Psychology as it pertains to people with physical disabilities. To accomplish this, the chapter will be broken into three sections, each with a specific role or task. The first task is to situate the current state of disability research surrounding people with acquired physical disabilities and explore through research, how the meanings of disability are constructed through various perspectives that are likely to influence the lives of persons with newly acquired physical disabilities, their family members and friends, and those they interact with on a daily basis. The second task is to explore the moment of rupture as individuals transition from being able-bodied to disabled, situating that the struggle is real and currently exist within a liminal position. Finally, the chapter will conclude by situating the importance of narratives as representations of cultural discourses, establishing a theoretical foundation and exposition of relational dialectics and pose the questions that this project will seek to understand.

State of Disability Research Surrounding People with Acquired Physical Disabilities

Acquiring a physical disability is a life changing, world altering event for any individual. In the United States, the risk of acquiring a physical disability before a person achieves retirement age currently hovers at 25% (Social Security, 2015). In addition,

currently half of persons living with physical disabilities are between the ages of 20 and 49. These numbers illustrate how common it is for a person to acquire either a temporary or permanent physical disability, yet the uncertainty that the general population of the United States has towards this community is still high as representation in various aspects of social life remain virtually non-existent.

The use of "acquired physical disabilities" is conceptualized then as a category encompassing a broad array of disabilities resulting from trauma or disease (Dunn & Brody, 2008, p. 413). Physical disabilities range from mobility impairment, loss or reduction of sight, vision or other senses, physical pain, discomfort or difficulty in performing daily (or everyday) tasks (ADA, 1990). Although disability may be defined, it should be important to note that no two disabilities are the same (Shildrick, 2002). More accurately, although individuals may share a label to their physical disability, their experiences in the day to day, their level of autonomy and their ability to "act" or "do" may vary greatly.

While explicating the body of research surrounding people with acquired physical disabilities, research can be categorized into two major categories. Before I describe the categories of research, it is important to note that research on people with physical disabilities has primarily been viewed through the lens of social deviancy.

In 1958, Goffman introduced the idea of stigma, which articulated that there are physical and relational characteristics that persons may possess that will be devalued by others who do not share in these characteristics. To more accurately speak, a person's differences may be viewed negatively by the majority. Murphy and Colleagues (1988)

argue that persons with physical disabilities share similar experiences to other populations of people who are devalued within our society. They continue with situating that by viewing persons with physical disabilities as socially deviant as provided contextual value to understanding the lived experiences of this community. This lens, one of social deviance has influenced disability scholars for decades as positioning physical disabilities against normalcy (able-bodiedness) allows space for theoretical and methodological tools to explore various levels of oppression leveled against this community.

The first category focuses on the lived experiences of persons with acquired physical disabilities. This research includes methodological approaches that highlight personal lived experiences through a critical lens (autoethnography and performance based studies), identity-related work (ethnography, interviews and focus groups), identity-politics and empirical research (surveying and testing theory) that espouses challenges individuals face on a day-to-day basis. Although academic conversations of history, day-to-day interactions and progress towards a positive view on life/well-being are discussed, this category specifically privileges the perspective and experiences of the person with the acquired physical disability as they negotiate themselves within an able-bodied world. Furthermore, this approach illustrates and highlights the voice of the individual through their own reported speech and/or their actions.

The second category focuses on the persons around and involved in the day-to-day lives of persons with acquired physical disabilities. This includes their family, friends, co-workers, teachers, aids, caregivers and other health care providers (i.e.

physical, occupational, recreational therapists, nursing staff, mental health professionals, etc). This body of research is not bound by time, and often illustrates the historical, social and potential impacts of having a physical disability on both relational and social contexts regarding everyday interactions, expectations and behaviors. This category of research privileges the communicative acts of the able-bodied individuals, their perceptions and communicative strategies that they use to create, build and maintain relationships with persons that have an acquired physical disability. A small portion of this research also uses auto-methodologies to explore and reflect upon the experiences of having a close family member with an acquired physical disability and how their experiences informed their viewpoint in relation to the individuals' with acquired physical disabilities. Within this approach, the voice of the person with the acquired physical disability is often left absent, or is only represented through the reported speech of the able-bodied individuals.

I believe that it is important to note that both approaches operate under the assumption that having a disability is both viewed and experienced negatively in relation to being able-bodied. This conceptualization is represented through both the lexical structure of the word disability, and how lived experiences of this population are reported within the different methodological bodies of research mentioned above. For instance, Bogart (2014) argues that having a physical disability can be considered having a marginalized identity. This identity is positioned negatively, not only to an able-bodied identity, but to other primary identities as well (race, gender, class).

Preconceived notions of disability are often foundational in the mistreatment of people with physical disabilities by able-bodied people. This mistreatment is due to the high level of uncertainty that most able-bodied people have in regards to what it means to have a physical disability when interacting with members of the disabled community (Farnall & Smith, 1999). In their article, Farnall and Smith provide empirical evidence that supports the claim that able-bodied people who have had prior experience interacting with members of the disabled community are more likely to have positive future interactions than those who have not had prior interactions with members of this community. This deficiency is credited in the lack of understanding by able-bodied relational partners.

Meanings of Disability: Social Deviancy and Establishing Legal Context

It is not surprising that there is a large amount of research outside of the field of Communication Studies, specifically research that focuses itself on work, productivity and accommodations. The disabled identity is constructed from the belief that the individual suffers the inability to accomplish certain everyday tasks due to a physical or cognitive impairment (Shildrick, 2002). In 2009, Shildrick further explicated the perception surrounding persons with physical disabilities though a historical account that spanned both legal, cultural and relational discourses. Over the past 25 years, the United States judicial system, in conjunction with the executive branch of the United States government has created a variety of federal laws and legal frameworks that protect and promote fair treatment for persons with disabilities. These changes, although intended to

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be positive, inadvertently reinforced the cultural discourse of autonomy and directly challenges how people with physical disabilities are viewed by an able-bodied society.

The most prominent and powerful of these frameworks is the Americans with Disabilities Act of 1990 (ADA). This act "prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, State and local government services, public accommodations, commercial facilities, and transportation" (ADA, 2015). Unfortunately, the language of this policy leaves the definition of disability fairly 0ambiguous, creating dissent within an already diverse community. The ADA defines disability as:

> An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.

Furthering this misunderstanding, the ADA does not have an exhaustive list of impairments and allows individuals, their friends and family and outside agencies identify and define disability within an individual. This can cause conflict between individuals as having a disability is not clearly defined or even understood.

The other prominent law was the Individuals with Disabilities Education Act of 2004 (IDEA) which was created to ensure that all children, regardless of ability, would be provided services and assistance for education and development. However, disability again is vaguely defined as a child:

> . . . with a disability means a child evaluated in accordance with Sec. Sec.

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300.304 through 300.311 as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as "emotional disturbance"), an orthopedic impairment, autism, traumatic brain injury, and other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services.

Within this act, we reinforce the social deviancy by evaluating children based on a series of arbitrary tests that need interpretation. Although a physical disability may or may not be present, the decision of need being decided by another discursively shifts power away from the child and their family to the educational system.

Both acts were created with the intention to help persons with disabilities become productive members of society by creating for them equal access and reasonable accommodations for both public and private spaces. However, as Soule and Roloff (2000) illustrate, these attempts at accommodation fail to take into account the actual needs of an individual, and provides support that is not necessarily needed for everyone. The passing of these acts, new challenges, social phenomena and relational conflicts have arisen as people with various types of disabilities have entered the workforce and educational systems.

Meanings of Disability: Historical Uncertainty and Cultural Discourses of Health

Historical uncertainty surrounding the lives of persons with physical disabilities are intimately connected to the cultural discourses of health and disability. While we can trace legal precedents that reflect societal views, the presence of a physical disability has always been negatively positioned to being able-bodied. This perspective significantly influences how persons with physical disabilities make sense of their own lives, as their sense-making is tied to the expectations of the larger whole. Braithwaite (1990) argued

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that when a person acquires a physical disability, they are literally forced to join a new

cultural group, one that is not within the majority and subjected to the knowledge of those

with social power. Historically, we can see this present through various legal, social and

relational mediums.

From the mid-1800's through the 1970's, as Shildrick (2002) noted, people with

severe physical disabilities were forced to be hidden away at homes and in asylums

(personal care facilities). In many cases, these people were not even allowed to be out in

public. One example arises from Chicago in the mid-1960's. A law in place at the time

confined people with severe physical disabilities and physical deformities from being in

public, lest they face a fine of no less than $1.00 USD and no more than $50.00 USD

(Chicago Municipal Code § 36-34, 1966). In some places, laws similar to this continued

to be on the books through the late 1970's. These laws reflect the cultural perspective of

the time towards people with severe physical disabilities, and also illustrates how little is

actually known about this community of people. Murphy and Colleagues (1988)

illustrate that anthropologist's study behavior to understand culture and hiding people

with disabilities from public sight keeps people segregated and in the dark about the lives

of this community. With the passing of the ADA of 1990, in addition to other

regulations, we find a grand shift in both the visibility and interactions between people

with physical disabilities and an able-bodied community. Today, these individuals have

more access and more autonomy when it comes to day-to-day tasks, but as Braithwaite

and Eckstein (2003) and Morella-Pozzi and Sunseri (2012) illustrate that there is still a

high level of uncertainty between able-bodied people and persons with physical

disabilities in understanding what is needed and necessary for individuals with physical

disabilities to be productive and work-ready.

In 2000, Braithwaite and Thompson edited and assembled a book that collected

research that utilized communicative research surrounding people with various

disabilities. In their introduction, they claim that part of their motivation of creating such

a text was to combat the misrepresentation of persons with disabilities within academic

research. In their seminal text, they review previous substantiated academic research that

claim persons with disabilities were often portrayed as:

> not well adjusted . . . [are stigmatized people that others] avoided . . . were
> unlikely to be selected as friends or colleagues . . . [experienced] a lack of
> attraction and [increased] avoidance . . . and noted greater interpersonal distance
> and distortion . . . and are perceived to be more reserved, alienated, introverted
> and distorted . . . (p. 4).

However, in their own research, found members of this community to be exactly the

opposite and were often very sophisticated in their communicative strategies as people

with disabilities often understood that able-bodied people were uncomfortable around

them and in-turn would take steps to help them alleviate their uncertainty (p. 7).

Much of the early research in Communication Studies, Behavioral Psychology

and Rehabilitative Medicine privileged communicative strategies that particularly

encouraged persons with physical disabilities to manage their privacy and boundaries in

positive ways with members of the able-bodied community. In 1990, Braithwaite

established that the discrimination and lived experiences that she encountered through

interviewing persons with physical disabilities was reminiscent of experiences she and

others have encountered with members of various cultural groups. In this research, her

premise outlined that persons with acquired disabilities could benefit from exploring

communication between able-bodied people and persons with disabilities as intercultural communication. In this piece, she explored how people acquired physical disabilities changed their communication habits from when they were members of an able-bodied majority to being members of a disabled minority. Her descriptive framework for the project utilized Deloach and Greer's (1981) three phases of adapting to disability to gain awareness and develop communicative strategies to utilize when communicating with the able-bodied community. This research laid a foundational groundwork for her to explore privacy boundary management when faced with unsolicited disclosure (1991), delegitimizing communication between able-bodied people and members of the disabled community (1996), and the exploration of social support through computer-mediated communication (Braithwaite, Waldron, & Finn, 1999). Braithwaite's work was truly foundational as it laid the groundwork for future research exploring the relationship between disclosure and disability (Duggan, Bradshaw, & Altman, 2010), the role of computer-mediated communication and educational accommodations (Bricout, 2001), access to social support via the internet (Sigal & Tali, 2011), and conceptualizing and constructing disability online (Carr, 2010).

As mentioned earlier, much of the research during this time period focused specifically on the reduction of uncertainty that exists between the able-bodied community and persons with physical disabilities. In 2000, Soule and Roloff explored the role of unsolicited help between the able-bodied community and persons with disabilities. Their conclusion included an explanation that the assumption that a person with a physical disability needs help is not based on external criteria, but rather on the

internalized assumption that they are unable to, or find particular activities more difficult and that assistance is always desired/expected. In the same year, Nemeth explored the communicative strategies employed in romantic relationships between able-bodied people and persons with physical disabilities, citing the assumptions and misconceptions that existed within the relationship and the different communicative strategies that are necessary for relational maintenance and satisfaction. Both studies, which were also published in Braithwaite and Thompson's (2000) book illustrate the lack of understanding of what it means to have a disability. In these cases, having a physical disability is seen as being disadvantaged and less capable of performing tasks and maintaining romantic relationships. This perspective is important as it is echoed through much of the current literature within our field.

Some of this uncertainty is due to the vague definition that the United States uses when defining disability (Harris, Gould, Ojok, Fujiura, Jones & Olmstead IV, 2014) while others argue the vastness of measurements necessary to truly evaluate the impact that legal frameworks like the ADA has on the lives of persons with disabilities within the United States is not practical or easily understood by the average person (Gould, 2004). Some scholars posit the lack of media representation negatively impacts what is known about people with physical disabilities, their lives (Shakespeare, 1994; Thomas & Smith, 2003), while some scholars situate the negative representations within literature (Thomson, 1997), and popular culture (Garland-Thomson, 2002; Lupton & Seymour, 2000) has led to the misunderstandings and ill-fated social interactions (Soule & Roloff, 2000) that occur between persons with physical disabilities and able-bodied people.

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Regardless of the cause to the uncertainty that exists between persons with disabilities

and able-bodied people, we can see that the lack of knowledge and understanding of what

it means to have a disability can and does have a negative effect on the interactions

between these two communities.

The cultural discourses of health and disability are highly influenced by the bio-

medical definition of disability (Miller et al., 1990). This definition posits that an

impairment is placed upon an unwilling individual that negatively impacts at least one

aspect of everyday life. This definition positions having a disability as undesirable and

negative in nature. (Darling, 2013) We can see the presence of the bio-medical definition

of disability in multiple areas of medicine from obstetrics and pediatrics to geriatrics and

end of life care. Today, newly expecting parents are expected to screen their unborn

children for a variety of physical and cognitive disabilities, with the

expectation/understanding that if the child does have a disability, that ending the life prior

to birth would be more beneficial than allowing the child to live a harder life (Darling,

2013; Nielsen, 2013; Shildrick, 2009). The biomedical definition of disability is

extremely powerful. In 2011, Shapiro reported that of the 1.6 million legal abortions that

occur each year, one percent is due to the mother being told that their child has some

form of manageable disability, while 12 percent [of the 1.6 million] have a severe genetic

defect. When surveyed, 50% of mothers report to choose abortion over life when faced

with news that their baby will be born with a disability, regardless of severity. Medical

testing and examination technology has been hailed as a method of preventing people

with disabilities from being born into this world and all of this is predicated upon the fact

that having a disability is both a negative attribute and inevitably makes an individuals'

life more difficult and less fulfilling (Hubbard, 1997).

The relationship between the historical uncertainty and the bio-medical definition

of disability is housed in the perspective of the able-bodied other. While intentions may

seem noble, many persons with disabilities have spoken out against this ideology, arguing

that life is and can actually be very positive and rewarding. One specific activist group,

Not Dead Yet, have worked tirelessly against the cultural discourse of health when it

comes to having a disability. Hyde and Rufo (2000) explored the varied rhetorical

strategies that this group used in speaking out against euthanasia and doctor assisted

suicide as it relates to persons with severe physical disabilities.

This perspective privileged the view of the disabled community, providing a

unique insight into an otherwise silent group. Other scholars have also worked towards

this goal and to further explore this idea, an analysis of auto-methodological and

interpretive research may shed more light into what it means to have a physical disability

from the perspective of the disabled individual.

Meanings of Disability: Embodiment and Performance of Disability While Existing

in Liminal Space

The body is the medium through which people experience their cultural world,

and bodily experience can reflect the culture in which it occurs. (Becker, 1999, p. 12).

Within the humanities, scholarship surrounding reflexive reporting of experiences of

individuals with physical disabilities has proven valuable by establishing insight into the

day-to-day and salient moments in which a disabled identity is called forth for validation.

One example of a recent autoethnography illustrates the embodied experience of having a physical disability on a college campus. Morella-Pozzi and Sunseri (2012) reflect upon the lead author's experiences of negotiating her relationships with friends, counselors and the University that she chose to attend for graduate school. In her autoethnographic reports, the lead author highlights the interpersonal struggles of uncertainty that she experienced with various able-bodied individuals, the power dynamics and gatekeeping present within an educational context and the feelings of invalidation caused by a bureaucratic system whose intentions do not fall into line with the goals of the institution.

The paper goes on to illustrate the relational/identity damage that comes from perceived intentions of a disability services counselor and the assumptions made surrounding the lead author's capabilities as a student and a human being. This essay situates not only the perspective of a person with a documented disability, but begins to explore the struggle of existing culturally within a liminal space.

> When [a person's] health is suddenly disrupted, people are thrown into chaos. Illness challenges one's knowledge of one's body. It defies orderliness. People experience the time before their illness and its aftermath as two separate realities. This perception of a dual reality-of the known world (the recent past) and the "bad dream" (the present) - constitutes chaos. (Becker, 1999, p. 37)

People with physical disabilities have long been viewed to exist in a liminal cultural state. Unlike people with severe illness, or as in recent months, been categorized and represented poorly through various outlets of media, persons with physical disabilities find themselves between states. These individuals exist within limbo. They are not ill, nor are they well. They are neither socially ostracized, nor are they recognized fully. This liminal state allows for them to be noticed and ignored within the same space (Darling, 2013; Luborsky, 1994; Murphy et al., 1988). Furthermore, people with newly

acquired physical disabilities find themselves struggling as they no longer are viewed as normal, nor do they truly understand or feel that they belong within the community of people with disabilities. Braithwaite (1990) identified a process that people with newly acquired physical disabilities undergo to change their communicative strategies in a manner that allows them to connect and be accepted by their new community.

Another example of a recent study is provided by Scott (2013) who provides a uniquely rich insight into the performance of disabled identity by analyzing and comparing reported experiences of persons with similarly labeled physical disabilities and contrasting them to her own performance of identity. This insight allows her to explore how her performance of disability provides privileges that can serve to further marginalize others with similarly labeled physical disabilities. This provides another sense of liminality as individuals with disabilities are often comparing themselves against others using ability as the measurement. This is illustrated through an example that emerged from a story shared by a woman slightly older than Scott. The woman being interviewed was about 10 years older than Scott, and throughout this article it is revealed that Scott was able to have a surgery while in her teens that allowed Scott to pass for being able-bodied (with an athletic injury), while the participant was never able to have the same surgery (due to not being developed yet). Scott's insight into this difference is important as it illustrates just how prominent our bodies are in how others choose to view our bodies.

Another scholar, Phillips (1990) explored the experiences between people with visible, physical disabilities and able-bodied people, and gathered stories that reflected

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how disabled person's experiences shaped their own self-image. In this study, Phillips suggested that positive experiences between these two communities lead to positive self-image, while negative interactions effected self-image negatively. The authors further posited that these experiences were likely consistent throughout US culture, and were framed not only through the content of the stories, but how the stories were told. In essence, a disabled identity is constituted within communication. This also provides value as the factors that shape self-image is intimately tied to the cultural discourse of self. "A central tenet of the cultural discourse of self: people are supposed to know who they are" (Becker, 1999, p. 103). However, as people interact, those interactions shape and change how people view themselves.

In two different studies, Lindemann (2008) and Lindemann and Cherney (2008) shifted from trying to understand how men who have acquired severe physical disabilities construct their understanding of disability to utilize and explore the performance of the disabled identity. By following a group of US Quad Rugby players, they concluded that men in chairs will enact multiple communicative strategies to construct meaning with able-bodied individuals and other men with similar physical disabilities in regards to their disability. One finding, similar to the one mentioned earlier with Scott (2013), expressed a liminal state as men negotiated their disabled identity in conjunction with other quad rugby players within an arbitrary classification system. In this space, liminality is constituted through the fact that these players are caught between being more or less able-bodied in comparison to other players (Lindemann, 2008). Another finding by Lindemann and Cherney (2008) found that the men in wheelchairs tended to enact hyper-

masculinized behaviors with each other and able-bodied men in an effort to fit in both relationally and within the cultural space. This enactment of hyper-masculinity is interpreted as a mechanism of establishing normalcy (able-ness) against the backdrop of disability. This finding acts as a precursor to Lindemann (2010) assertion that able-bodied men view physically disabled men as female or lesser. By enacting masculinity in hyperical fashion, they are essentially trying to pass themselves off as both equal and "normal."

Approaching the acquisition of disability through performance and embodiment situates the important role that the body has in meaning construction. In each of the above examples, performance and embodiment of disability are present, all the while individuals with acquired physical disabilities are forced to negotiate liminal spaces. The liminality resembles the Catholic churches notion of Limbo, which is a space located on the edge of Hell in which a person is held until they earn their spot in Heaven through redemption. People with acquired physical disabilities find themselves in their own version of limbo, a liminal state, in which they are not viewed as normal (able-bodied), and due to changing legal frameworks, and shifting cultural discourses, nor are they being viewed as completely helpless. Through the extant body of research, people with physical disabilities have found themselves negotiating uncertainty not only within constructing their own meanings of disability, but finding that our culture also has varying understandings of disability that are shaped by these tensions. Outside of Braithwaite's (1990) claim that there should be study specifically targeting the cultural group of people with newly acquired physical disabilities, very little research in our field

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has focused on acquired physical disabilities, while rehabilitation science, sociology and anthropology have focused primarily on the liminal states that people with acquired physical disabilities experience when trying to make sense of their lives post-disability.

To explore the phenomenon of the meaning-making of disability, researchers have consistently framed their study through a lens of social deviancy, recognizing that power is privileged with what society views as normal. Scholars have recognized and studied this liminal tension from both an insider and outside perspective, yet the majority of research is focused on the individual(s) and their behavior. This study proposes a shift of focus away from the individual(s) and into the words and language that actually create the discourses identified by other scholars.

Language gives access to a world of experience insofar as experience is brought to language (Becker, 1999, p. 14). This project seeks to explore this phenomenon by looking at the narratives and stories that people tell while positioned in a liminal state.

Exploring the Rupture: Using Life Stories to Identify Cultural Discourses

Our stories are told in a manner that help not only frame how we want others to understand our experience, but reflect our own understanding of our lives. These stories communicate culture insofar as to situate and identify the cultural rules that influence behavior, expectations and communicative strategies. Becker (1999) goes as far as to argue that stories are "a culture-specific response to disruption" (p. 45). Acquiring a physical disability is very much a disruption to the lives of the individual, but also to those within their social network [family, friends, co-workers, etc.]. This disruption [acquiring a physical disability] acts as a point of rupture as Braithwaite (1990) points

out, people who once belonged to the majority, now belong to the minority, and in many cases, wake up belonging to a new community.

Using life stories to identify cultural discourses emerge from people who question who they are, after acquiring a physical disability. Becker (1990) identifies that many of us take for granted our social world, and when we are forced out of our predictable routines, we are forced to create new contingencies to handle life challenges. The collection of a person with an acquired physical disability's life story provides continuity as we follow their negotiation of meaning of disability. This process illustrates the point(s) of rupture that this population experience as well as identifies the various cultural and relational discourses that shape their perspective.

When a person tells a story about themselves, inevitably they share with their audience, how they view the characters (themselves and others), the plot (their experiences), conflict (challenges that they face), and the various themes (discourses that shape how events are expected to unfold). Raggat (2006) also illustrates that their choice in which story to tell to represent various points of their lives is also telling as the very nature of the choice is dialogic in nature. The choice in story told demonstrate that individuals make conscious decisions on how they want to be perceived and what they want others to know. This disclosure (privacy and/or boundary) management is a result of cultural and relational expectations. One theory, a recently re-articulated relational dialectics is positioned very strongly to explore how these stories come to be and how meaning is made from the telling of these stories within that moment. Relational Dialectics was initially intended to be an interpretive theory of communication that

grounded relationships in a web of contradictions (Baxter & Montgomery, 1996; Rawlins & Holl, 1988). The original form of this theory situated relationships as a social process, continuously moving, changing and thinking. In 2004, Baxter began to lay foundational groundwork was laid to situate the new articulation of Relational Dialectics, shifting us away from trying to understand relationships within containers and focus more on the "complex process of meaning-making" that emerges from relating. In 2011, Baxter unveiled the new articulation of Relational Dialectics (or RDT 2.0), which now functions as a tool to be used as a heuristic device that clarifies and describes the complexities of meaning making within communication.

Both versions of RDT have been based on the work of Mikhail Bakhtin, a Russian philosopher, scholar and literary critic (1981, 1984, and 1986). His work, which was labeled by Holquist (2002) as dialogism, was an approach to meaning-making through relating to the self and the social world. This approach privileged that meaning is constructed through the interplay of multivocalics, or multiple discourses competing within the moment. Bakhtin (1981) and Baxter (2011) argue that within every act of communication (Bakhtin labeled this an utterance), is a site in which discourses compete and interpenetrate each other to create meaning. Bakhtin further explained that no two interactions would be the same, as a reinterpretation is necessary for meaning to be made, even if the same content re-occurred (Baxter, 2007; Bakhtin, 1981).   This reinterpretation is bound to the notion of the chronotope, meaning space-time, and that between each turn of talk, an utterance must be re-engaged with what is gained from prior knowledge.

Theoretical Foundation of Relational Dialectics: An Exposition

Both Baxter (2011) and Bakhtin's (1981, 1984) work is centrally focused on the idea of dialogue, but not in the traditional sense of two equal voices, shared within a moment and bound in exchange between self and Other. Instead, Bakhtin positions dialogue as conversation between "the one" and "the other" and is "multi-vocalic, with multiple radiants of meaning" (Baxter, 2004, p. 108). Holquist (2002) positioned Bakhtin's focus on dialogue as a direct criticism to growing up amid a civil war andintellectual oppression and persecution enforced through a Stalinist regime and focuses primarily on the inter-relatedness of our social worlds. Dialogue then becomes as simple as a space where multiple voices are heard. However, to complicate this, the physical voice itself becomes less important than the representation of multiple voices (discourses) within a turn of talk. In this space, relational partners call into existence the competing discourses that shape meaning within their own relational experiences. For people with newly acquired physical disabilities, these discourses are not only based on what they are currently experiencing, but also what social norms, pressures and expectations frame as normative behavior.

This approach to the importance of multiple voices is central to why Baxter re-articulated RDT. Bergen and Braithwaite (2009) argued for the importance of expanding how we look at individuals and their relational partners, privileging that studying the discursive struggles involved in meaning making provide a unique insight into understanding how discourses, or systems of meaning (Baxter, 2011) shape relational interactions with others and their social worlds. RDT also forces power to be re-

evaluated as discourses very rarely carry equal weight when engaged within an utterance. Baxter labeled this process as discursive struggle, where centripetal discourses are privileged and located at the center, while centrifugal discourses are often marginalized. Another method of looking at this discursive struggle is to view where they exist.

Centripetal discourses are often considered to be normal, or are widely accepted as natural (Baxter, 2007, 2011). This viewpoint may even emerge as obvious or "the way things are." While centrifugal discourses exist on the margins and are often viewed as socially deviant, or different. This viewpoint may be viewed negatively by the general population, or even denigrated through every day talk as, "silly" or "not-practical." What is important to note is that in RDT, these discourses tend to always be in flux. Meaning, they are engaged in a struggle in which they both can and often exist within an utterance. This flux, or as Baxter (2011) labels, "the push and pull" (interplay) are where meanings become established, or gain normalcy, or where new meanings may emerge. This struggle is where disparate discourses can come together or pull apart, in some cases, they can even completely change.

Bakhtin (1986) introduced us to the idea of the utterance, which Baxter (2011) adapted as a turn of talk. In both articulations, an utterance exists as a link in a larger utterance chain, one that is marked by multiple strands of discourse. Baxter (2011) uses Bakhtin (1986) to position an utterance as:

> . . . a profoundly intertextual social unit . . . Simply put, each individual utterance can be thought of as the site in the utterance chain where already uttered discourses voiced by others come together with discourses anticipated in others' responses . . . Meaning making happens in the utterance chain – the "chain of speech communion (p. 50).

An utterance always finds itself couched between prior utterances and future utterances, metaphorically represented as links in a chain. Some utterances are "quite distant in both space and time; these distal links represent the already-spoken utterances of the distant past that occurred prior to a particular conversation" (Baxter, 2007b, p.   256). These links permeate our talk and provide dialogic overtones to our meaning making.

While some utterances find themselves distant, other utterances are positioned much closer in both space and time and may precede or position itself in direct connection to the current conversation. These dialogic overtones are labeled as proximal as the connection to the conversation is tightly bound to the immediately preceding utterances and immediately proceeding utterance.

Baxter (2011) continues to typify these links of utterances by identifying them by "already-spoken" and "not-yet-spoken" categories. These categories refer to the aspect of a link you are interested in understanding. Already-spoken links refer to past or prior utterances. These utterances could be drastically distant in both space and time, sometime uttered by the individual speaking or others regarding the topic. Not-yet-spoken utterances refer to either the anticipated direct relational or potential relational responses to an utterance. These links are interdependent of one another and as Bakhtin (1986) states, "each utterance refutes, affirms, supplements and relies on the others, presupposes them to be known, and somehow takes them into account" (p. 91).

For RDT, the distal, already-spoken link refer to utterances circulating the culture at-large. These utterances are called into reality when voiced by a speaker (p. 50). These often manifest themselves through language that support cultural positions or values. This

link influences how culture is being reconstituted within the moment by allowing different systems of meaning to interact. This study focuses primarily in the distal, already spoken and delves briefly into the distal, not-yet-spoken link.

Distal, not-yet-spoken links find themselves concerned with the potential future response or evaluation conducted by someone other than the listener of one's self based on the utterance. This concern helps shape how messages are created and interpreted. It also speaks to how we want our identities to be perceived by others and what face we want to put forward (Baxter, 2011, p. 113). This link also speaks to the power of how language can be used to shape our social realities as a misspoken phrase or position can have detrimental effects in how an individual could be perceived in the future.

RDT draws upon Bakhtin's experience as a literary critic and utilizes texts to identify discourses. In this, Baxter encourages the choosing of texts to focus on what she labels as dialogically expansive, or texts that are rich with contradictions and ruptures. The fact that the idea of disability is widely understood from a space of deviancy, makes studying the population of people a logical choice. Furthermore, the fact that a large amount of the research situates people with physical disabilities as existing in a liminal state, specifically after they have acquired said disability, makes studying their life stories a logical starting point in exploring how competing discourses shape and animate the meaning of disability.

Research Question

This review of literature on people with physical disabilities has illustrated a number of very interesting and insightful studies surrounding people with physical

disabilities. It has also created an overabundance of questions that disability scholars still need to address. However, this study cannot seek to complete all of them, but rather lay a foundational groundwork for understanding how the discourse of disability is shaped by various cultural and relational discourses present when existing in this liminal state. The first step in this process begins with the following question:

RQ 1: What discourses animate the meaning of disability for persons with newly acquired physical disabilities?

CHAPTER THREE: METHODS

In an effort to explore, identify and expand our understandings of the discourse of an acquired, physical disability, this study engages qualitative methodologies, including semi-structured interviewing and a critical thematic discourse analysis of twenty life-story interviews framed within disability. More specifically, this study used an adapted form of McAdams life story interview protocol that asked participants to share stories surrounding ability (See Appendix A). As participants recount stories from their lives, their choice in story represents a dialogical negotiation of self as they represent specific moments within their lives. Raggat (2006) constructs the act of choosing which stories to share as a dialogic moment.

Participants

    Eligibility. A total of 20 participants were interviewed for this study. To participate, individuals were bound to a particular set of criteria that was self-identified based on the posted requirements for the study, initially shared via Facebook (See Appendix B). Specifically, participants needed to be over the age of 18 years. This requirement was structured due to the interview protocol by McAdams (1993) as he stresses the importance of interviewing adults as it is important for participants to talkabout different chapters within their lives, portions of their childhood as well as portions of their adult lives.

Next, participants within this study identified with acquiring an actual diagnosis of having a physical disability within the past three years. This study frames a newly acquired physical disability as any permanent impairment that requires the use of an adaptive mobility device (wheelchair, prosthetic limb, cane, walker, or symbol cane) to help aid in everyday activities, such as eating, bathing, and/or moving from a stationary position to other locations; Or have an acquired (by disease or accident) impairment that prevents, hinders or complicates their ability to perform daily tasks that were once done normally. The self-identification is relevant for this study as various participants, as well as others within the community of people with acquired physical disabilities have different experiences with rehabilitation and re-integration into everyday life (Tagaki, 2011).

Recruitment. Initially, this study was planned and approved through the University's IRB protocol to recruit participants through three mediums: Facebook, personal and professional contacts, and distribution of the call through e-mail and internet networks. From three initial participants who responded via Facebook to my initial call, an additional 17 participants were recruited through word-of-mouth/snow-ball sampling. As finding persons with newly acquired disability is difficult, and members of this community are considered hard to find, snowball sampling was employed to reach a sample size of twenty (Noy, 2008). To conduct snow-ball sampling, at the end of the interviews, participants were given my contact information (telephone and e-mail address) and asked to pass along my information to others who qualified for and might be interested in participating in the study. Once I was contacted, I e-mailed each individual a

copy of the study call with instructions to read through the call to see if they would be a good fit. From this, 27 contacts were connected with me, and 17 interviews were conducted. Each interview was conducted within 30 days of initial contact, with a majority occurring within a two-week window of initial contact. As location and accessibility can be an issue for many people with acquired physical disabilities, each interview was conducted via a face-to-face skype interview and ranged from 49 to 141 minutes. This range was larger than expected, with an average length of 89.05 minutes, variance was due largely to length of stories shared. Interviews were arranged based on participant availability in time and technology and were all conducted from the participants' home. Upon concluding the interview, a secondary e-mail follow up provided each participant a series of local an online resources was created in the event of emotional distress.

Demographics. Participants for this study were recruited through social networks from ten states (Colorado, Nebraska, Texas, Minnesota, Iowa, Wisconsin, Illinois, Florida, New Jersey and Washington). Individuals ranged from 26 to 44 years of age, with an average age of 33.45 (S=4.94). Overall, participants identified with a diverse range of disabilities, one with paraplegia (5%), one with quadriplegia (5%), four with blindness (20%), two with late on-set rheumatoid arthritis (10%), one with juvenile rheumatoid arthritis (5%), four with traumatic brain injury (20%), three who experienced a stroke (15%), one with fibro myalgia (5%) and three with permanent physical injuries (15%).

Sex, gender, education and income level were not specifically collected for this study. This choice was made during the conception process and was not directly connected to the goals of this project. In hindsight, this was a mistake and throughout the interview process, this information was revealed both explicitly in their stories and implicitly in what they talked about or through the methods of recruitment. Since there is not specifics in every case, this information is left out of this section.

Procedures

      Adapting McAdam's life story interview protocol. This study employed an adapted form of McAdams (1993) life story protocol. The original protocol was created to collect from participants a variety of stories and narratives that shed light into how they view their lives. I adapted this protocol to focus on how a person's life story is understood through the concept of having a disability. Specifically, I added language to each story prompt that focused specifically on how participants thought about ability/disability throughout these experiences. There are a total of seven sections, with 22 story/narrative prompts that focus on the past, present and future. In addition, the protocol asks participants to reflect on various values, beliefs and hopes for the future by having them construct narratives to reflect these attributes. Raggat (2006) situates this type of protocol as dialogic, as the internal decision making process within a participant on which story to choose to tell is a powerful statement in how this individual not only constructs their understanding of reality, but reflects their inner-struggle to frame their identity through their experiences told through a single narrative.

The protocol starts with my own experience as a person with an acquired physical disability. This story was important for the protocol in two primary ways. First, it allowed the participants to know that I was a part of the same community, providing me 'insider status' and alleviating innate fears participants might have in not understanding their experiences (Dwyer & Buckle, 2009). Second, my story allowed participants an insight into the various chapters of my own disability story and provided a model for detail when sharing their own story.

Once I had completed my story, I began with the protocol instructions initially constructed by McAdams (2003). This set the tone and previewed the seven parts of the protocol for each participant. The protocol then starts with asking participants to frame their life into chapters, similar to a book's table of contents. They were asked to identify chapter titles and a brief synopsis of each individual chapter and to identify key characters from each of these chapters. Although relatively brief, this portion of the interview sets a narrative tone and allows participants to begin structuring their thoughts chronologically for the interview.

The next portion of the interview elicits key events from the participants' disability stories. Eight story prompts in total collected vivid and important moments for each individual's narrative. Story prompts ranged from positive and negative childhood memories as they relate to ability to a vivid adulthood memory and a significant turning point in having a disability. This portion of the protocol collected snapshots into the participants' lives and at times created strong emotional responses within the participants.

The protocol also set the tone for the third portion of the protocol, which focuses specifically on their vision of the future.

The third section of the protocol focuses specifically on future events and hopes that the participants have relating to goals and achievements. The first portion of this section linked the memories they had just shared to where they see their life going next. Afterwards, participants were asked to share hopes and dreams, while concluding with a life goal or project that they may be conceptualizing or currently working towards. This section of the protocol also set forward a foundation for talking about challenges that these individuals face on an everyday basis.

The fourth section of the protocol asks participants to reflect upon challenges and hardships that they face that relate to having acquired a physical disability. This section consisted of four story prompts that included challenges, loss, health and failure. Although negative, the stories allowed participants to frame their experiences in ways that displayed perseverance and fortitude. This section also constructed the ability for participants to start thinking about the tools they used when faced with adversity.

The fifth section of the protocol asks participants to reflect upon their personal ideologies. Participants were given questions relating to religious, political and social influences that allowed them to articulate their core values. In addition, two questions relating to what they believe their single most important value is and if there is any other moment in their life that stands out as particularly meaningful.

The sixth section of the protocol asks the participants to construct a life theme from the stories they have just told. By looking at their past, present and their potential

future, participants were asked to reflect and concisely articulate what theme(s) might underpin their experiences. During this portion of the interview, participants reflected and called up their redemptive qualities that they identified in the fourth section of the protocol.

The seventh and final section of this protocol provides participants the opportunity to reflect upon the experiences of the day and provide feedback to the interviewer. This section allowed participants to not only reflect on the experience as a whole, but share their feelings that they experienced during the process. During this section, participants were also able to ask me questions. This is common within interviewing and often acts as a catch-all or clearinghouse question (Kvale, 1996).

Pilot. Prior to interviewing participants, I took a number of steps to ensure the quality of using this adapted protocol. As this protocol was initially developed by McAdams (1993), and adapted for this study to collect a participant's disability life story, I wanted to know before interviewing participants, the challenges I may face in the interviews itself. To explore the potential challenges and pitfalls, I used two primary methods of discovery. First, I conducted three pilot interviews with the adapted protocol on close friends from my undergraduate years. These friends all had acquired physical disabilities, but were not within the eligibility range of this study. By conducting these interviews, I was able to get a feel for the protocol and engage in crafting probing questions when stories ended abruptly or were hard to construct for the participant.

Second, I was able to approximate how long each interview would take. Second, I assigned the original protocol to three undergraduate interpersonal communication

courses as their final project, interviewing specifically a family member and a friend. Their feedback while presenting their results helped me understand the nuances in the challenges they faced implementing this protocol. Specifically, they were able to help me articulate the emotional toll for both the participant and the interviewer as this protocol asks a lot from the participant.

Once both methods of discovery completed, I was able to more accurately explain the process of the interview to my participants. I was also able to emotionally prepare myself to ask in most cases, a complete stranger to divulge a significant amount of information, in the form of personal life stories. As Bochner (2001) states, stories beget stories, and this protocol does not allow the traditional back and forth of stories and self-disclosure, and although the participants seemed more than willing to share, the emotional closeness that this protocol creates was not reciprocal. More than one participant mentioned at the end of their interview on how they had not talked or shared a lot of the information before. When prompted with if they had any questions for the researcher (me), they responded with inquiries on whether or not I had experienced similar events.

Data Collection

Prior to each individual interview, each interviewee was explained the nature of the protocol and a brief explanation of my dissertation topic was given (See Appendix C). Afterwards, they were instructed about their willingness to participate in this study andasked to identify themselves and give consent on an audio recording that was created through audacity, a common audio recording tool for computer use. This recording was

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then coded numerically and a separate, but corresponding recording was numbered to protect the participant's anonymity.

Upon completion of the interview, I made small talk with participants and thanked them for their willingness to participate. In addition, I asked them to think about anyone else they thought might be eligible and willing to participate in the interview. I provided each person with a fresh e-mail call (See Appendix D) to forward onto them and at least one contact for a local and online support center for any emotional distress that they may have faced while participating.

Since each interview was digitally audio recorded, both the acknowledgment and the interview file was uploaded to a cloud based storage service. The files remained separated by unlinked accounts. Once stored, eight of the interviews were parsed and sent to a professional transcriptionist, while the other twelve were transcribed by myself. After receiving the first eight transcriptions from the service, I performed an accuracy check to ensure that the transcription matched the recording (Cresswell, 2013). As I performed all the other transcription myself, a quality check was performed upon completion.

Data Analysis

Data for the study was analyzed using a discourse specific thematic analysis introduced by Baxter (2011). The choice to use Baxter's method follows the procedures of mainstream thematic analysis procedures, such as Strauss and Corbin's (1990) constant comparative thematic analysis or Glaser & Strauss (1967) grounded theory analysis. Using this method requires for a phenomenon, event, object or setting of interest to be identified (Baxter, 2011, p. 29). For this study, a broad analytical question was

used, "What is a disability?" This question created a setting and provided an object for analysis.

Selecting a Text

Using McAdams (1993) life story interview protocol provides rich narrative data for analysis. Baxter (2011) suggests that narratives provide a rich and thought-provoking set of data that is ripe with opportunities for analysis. In each story, multiple voices emerge to give saliency to discourses that are present within the moment. As the goal of this study is to identify the discourses of a newly acquired physical disability, using narrative-based data allows for specific events to be analyzed by how a participant talked about the events.

As mentioned above, McAdams (1993) life story protocol included seven section in total and can take upwards of two and a half hours, decisions were made to create a manageable and accurate data set to work with. For this analysis, only certain sections were included as to focus on the analytical topic: What is a disability? With this in mind, the first four sections of the interview were used for analysis. Once the text has been identified, I split them in half, saving 10 interview transcriptions for the discourse verification process.

Identifying Discourses

The first step in this process is to understand the current social, historical and political discourses that currently exist surrounding the concept of disability. This process entailed reading and engaging with the academic conversation. As research within this area is spread across the social sciences, texts from rehabilitative science, anthropology,

sociology and psychology were engaged in addition to existing communication based research. Baxter (2011) argues that this process sensitizes the researcher and helps position data within in a larger framework.

This study employed Braun and Clarke's (2006) six steps to a thematic analysis as a guideline to identifying the discourses of an acquired physical disability. Braun and Clarke state that a thematic discourse analysis begins by being reflexive of what you are collecting and what you are reading as you move through the data to get a feel for what is happening within each story (p. 82). This process differs slightly from Baxter's (2011) method, as RDT positions the contrapuntal analysis as a specific tool to identify and explore discursive power. As this study did not do a full contrapuntal analysis, Braun and Clarke's thematic discourse analysis was appropriate in identifying the various discourses of disability.

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Step One: Create Familiarity. This process was conducted by re-reading and listening to the interview recordings both while transcribing and while reading the finished transcripts. A few of the longer interviews were played in my car while traveling to and from the various campuses that I teach at. Each transcript was read at least three times, while a few were read an additional time.

Step Two: Create Codes. The codes created for this data set are based on the analytical question, "What is a disability?" This was then converted into a semantic object, "Disability." This process allows for the object to exist within a larger context (discourse). Baxter (2011) describes this more accurately by framing the semantic object within an utterance chain. This chain consists of all the cultural and relational discourses of disability, the present moment and the ways that this utterance, or in the case of this study, this story was constructed with the potential future utterances/stories in mind. This idea is adapted from Bakhtin's (1990) notion of addressivity and super-addressivity, positing that all communication is directed towards someone and can effect and inform others who were not necessarily the intended audience. This process is explained through questioning the role of the specific utterance, which in this study took the form of a story.

Using the semantic object, a derivative of the analytical question, initial coding began. As I read through each story individually, I coded text from the story as it related to my semantic object. As I was reading, I would ask myself, "What is a disability?" and each time a story, idea or concept was present that would address my question, I highlighted it. Through this process, I began to create a list of coded discourses.

Step Three: Create Discourses (Themes). Once I had completed the initial coding, I began to compare my coded data against each other, grouping different statements and stories together based on similarity. Throughout this process, an in-depth research log and memo were created, annotating and listing direct quotes and exemplars, and coding statements in different colors. This process produced three distinct discourses: 1). the bio-medical discourse of disability, 2). the socio-performative/linguistic discourse of disability and 3). the bio-political discourse of disability.

Step Four: Review Discourses (Themes). Once the discourses were named and identified, a definition with an in-depth description and exemplars were created. A review of the exemplars was necessary to define the boundaries of the discourses and to ensure that there was little to no over-lap within the tenets of the identified discourses. This step is similar to Braun and Clarke's (2006) thematic analysis procedure.

Step Five: Defining Discourses (Themes). After completing the review of discourses, a robust, analytical memo was created outlining each tenet that constructed the discourses identified. This process included labeling, identifying and marking specific exemplars from participant stories that illustrate the discourse within the text. Each tenet is identified by a number of exemplars.

Step Six: Use of Exemplars. Using exemplars for this process involved identifying specific passages of spoken dialogue from participants as they shared their story. Context became important as these discourses were invoked in their choice of words and how their perception of these events were shared in specific ways. Exemplars provide an important tool for us to understand exactly how each participant understood their experiences through their choice of language.

Verification Procedures

Although this work does not seek to predict or explain how a phenomenon works, there is an importance placed on ensuring that data is analyzed with rigor, validity and reliability in mind. To accomplish this, three different verification procedures were used. These methods have been used in other discourse based analysis (Baxter, et al., 2014; Suter et al., 2015; & Suter et al., 2014). The verification process included: Referential adequacy, audit trail and data exemplars.

Referential Adequacy. Lincoln and Guba (1985) situate referential adequacy as identifying and archiving a portion of data. Using the remaining data, conducting the analysis, and then using the archived data as a way to test for validity. For this study, I split the data in half and conducted my analysis on the first portion. I then used my findings and compared the data from the archived interviews.

Peer Review Process. In addition, I provided a robust description of the discourses to two people, trained in discourse analysis for their verification of my findings, using the second half of data. This process occurred twice.

The first time, a person trained in discourse analysis was given the second half of the data with descriptions of the two discourses identified. They looked over the data, identified contradictory evidence, and a recommended a new review occur. In this instance, the reviewer found instances where a difference in able and disabled language occurred within the same discourse. In these stories, meaning was changing due to participant's choice to intertwine abled language with disability-specific language within an utterance. This caused the discovery of the sociolinguistic and biopolitical discourse of disability as being different and unique.

The second time, after another round of data analysis, a second person trained in discourse analysis verified the newly articulated discourses by using the second half of the data. However, examples of the bio-political discourse of disability were initially positioned as a separate discourse of disability and was not positioned with the sociolinguistic discourse of disability. This became problematic, as the language being identified could really be read into either discourse. A short time later, I had a conversation with my advisor, who suggested that I look at whether the discourses could fit into a larger cultural framework, which spawned the Disability Discourse of Normalcy.

This process is important for displaying rigor and validity to this project. Using the second half of the data, it is important that each discourse and all of the tenets are represented in the second half of data. The difficulty of this project was partly tied to the huge differences that exist between acquired physical disabilities. The second round of verification provided valuable insight in describing these discourses.

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Audit Trail. In addition to referential adequacy, Lincoln and Guba (1985) advocate the usage of an audit trail. As I have already an extensive set of notes, an audit trail was created so that an explanation of each step and decision has been documented. In addition, all notes from the two people who verified my data is also included within this audit trail. As Malterud (2001) states, "the reader needs to know the principles and choices underlying pattern recognition and category foundations" (p. 486). The second reviewer was given access to my notes, but not the first reviewer to ensure that there was no cross-contamination.

Data Exemplars. This method serves two primary purposes. First, as Norwood (2013) argues, exemplars are used to ensure that the exemplars are fully representative of the larger narratives that the discourses emerge from. By providing exemplars, I had the ability to illustrate the presence of the discourse within the speech of the individual. Second, exemplars are used to create verisimilitude within the reader (Burnard et al., 2008). This creates a level of connection and believability that is often absent or confusing for an audience.

In total, sixty-one exemplars were pulled from the first four sections of ten interviews. These exemplars were carefully chosen as they reflected truth within the larger narrative of the individual as well as connected to the discourses of disability that are present in this study. Once the exemplars were identified and labeled, they become another level of verification for the validity of this study as they provide consistency within the results. An additional 13 exemplars were found in the second half of the data by the reviewers as great examples for said discourses.

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In the following chapter, the results of this project will be reported using exemplars to frame and illustrate the differences in the two discourses of disability present within this study. The latter discourse is framed with two minor discourses and the subtlety between them is framed using abled and disabled language

CHAPTER FOUR: RESULTS

This study focused on exploring how persons with newly acquired disabilities made sense of what disability means. Through this exploration, two primary discourses emerged, with the latter discourse manifesting in two distinct ways.

The first part of this chapter seeks to explore how participant experiences shared through narrative has illustrated the various tenets of the biomedical discourse of disability. Using an in-depth look into the tenets that constructed each discourse and providing exemplars to highlight the subtlety and nuance of each experience will demonstrate the nuances of each discourse.

The second half of this chapter will juxtapose the biomedical discourse of disability with the disability discourse of normalcy by employing the socio-linguistic and the biopolitical discourses of disability. Finally, the chapter will conclude by briefly painting a holistic framework that positions the biomedical discourse of disability with the discourse of normalcy.

This study allowed participants to self-identify the moment they acquired a disability, and although some were aware of the inevitability, or experienced the gradual loss of a central function within their body, every single person spoke of the moment as a sudden and permanent shift. More specifically, each person chaptered out their life with pre-disability and post-disability as being uniquely life changing, abrupt and hard to explain. I believe one user illustrated this point the best,

You know, I have adapted and adjusted and I am okay with everything, you

know, but that moment that I came out of surgery and I couldn't see anymore, you

know, that moment was surreal. Like, I knew then I wouldn't see anything

anymore . . . the blurry sunset, the flashes of color, the outline of my mom, I just

wouldn't experience it like I used to, you know. My mom asked me what it was

like, and it's – it's crazy. I am experiencing it, and I tell them that I can't see, but

it's not that I can't see . . . but I can't see you know? (02: S2P3).

This passage references a very centralized experience that every single person articulated.

The moment that they acquired their disability was an abrupt shift.

Another participant spoke of the moment she realized that she was actually

disabled:

The moment that I first realized I was disabled was not a long time coming . . .

[she narrates a longer story of her life pre-acquisition] . . . one moment I was on

top of the world. I modeled, I was earning my PhD and you know the next, I am

lying on the floor of my home, covered in my own shit, without the ability to

clean myself up. It was sobering . . . I could not for the life of me, understand

what had happened (05: P2S2).

Participants often described this experience as a surprise, sometimes articulating this

emotion in tandem with embarrassment and in one case shame.

I became disabled because I made a poor decision. I knew I shouldn't have done it

[car accident relating to drug usage] but now I can't take care of myself. I have a

caregiver who gets me dressed, helps me you know, go to the bathroom, and I

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can't even wipe my ass man . . . I don't know what else to say about it. My mom

has to help me clean myself up and you can guess, you know I am sure you know

what I am talking about, but it's shameful. It's like I am a kid (07: P4S2)

Throughout the interviews, participants' reactions to how and why they acquired

their disability varied. As noted in the methods section of this project, participants ranged

in type of disability from chronic illness, sudden on-set illness, accident, and disease.

Each participant identified the moment they acquired their disability as not only sudden,

but unplanned and undesirable. These reactions mirror the biomedical discourse of

disability. Each person at some point framed disability as a problem. For the participants,

problem can be constructed in a number of ways. However, each story shared in this

manner, portrayed having a disability as a challenge, being negative or in some way

undesirable.

Similar to how current disability scholars have talked about the biomedical

discourse of disability, the biomedical discourse frames having a disability as undesirable

and often a solitary characteristic (Barton, 2001; Darling, 2014; Hiranandani, 2000;

Shildrick, 2009). This is further supported by the fact that every single person who

participated identified and narrated the moments surrounding the moment they acquired

their disability. Even those whose acquisition seemed gradual, identified and spoke to the

moment they became disabled as sudden, startling or surprising.

Throughout this chapter, the different tenets of the discourses used are a

combination of discourses of disability that have been found by other researchers, as well

as myself. To make more sense of how these discourses have been identified and put

together, it is important to understand how diverse the field of disability studies are. You will see that where tenets are cited, that portion of a tenet comes directly from the work, while uncited tenets emerged from the text.

The Biomedical Discourse of Disability: Narrative Experiences of Persons with a Newly Acquired Disability

The biomedical discourse of disability is the current, virtually monologic discourse of disability in our world today. When trying to understand meaning-making and disability, it is inevitable to have to find space for this discourse. It is present in our history, our cultural, relational and social discourses and has impacted every aspect of our popular and relational cultures (Darling, 2013). This discourse is constructed by three primary tenets and two ontological assumptions.

The three major tenets of this discourse are (1) having a disability is an undesirable trait that some people possess. A disability is constructed as an unwanted condition, diagnosis or state of being that is unplanned and majorly impacts a persons' self. (2) The second tenet of the biomedical discourse of disability is that we assign value to a persons' abilities. This tenet values appearance, with the more disabled a person looks, the more undesirable they become. This tenet also encompasses that those who are disabled are unable to perform everyday tasks or life activities. (3) Finally, the identity of disability is driven and sustained by stigma. Initially introduced by Goffman (1963) stigma can be understood as an attribute that a person has that is classified as an undesirable trait or stereotype. This tenet positions disability as the inability to perform

everyday tasks and is fundamentally communicated this way in virtually every communicative space.

The biomedical discourse is steeped in the legal, medical and societal history of this country. A disability historian frames the treatment of persons with disabilities within our country as being situated in the inability for persons with disabilities to live independent, productive lives (Nielsen, 2012). Shildrick (2009) argues that this belief perpetuated our belief that persons with disabilities need to be taken care of, or to be cared for. Further looks into the past shows a history of mistreatment, sterilization and legislation that actively worked against integration, interaction and understanding of an entire community of people.

As recently as 2013, approximately 50% of abortions conducted were due to mothers being told their children were to be born with some form of disability (approximately 1.3 Million) (Hubbard, 1997). Another case from 2012 highlighted the struggles that a woman with a developmental disability had in trying to prevent her pregnancy from ending in doctor-ordered abortion, and then sterilization. The mid-2000s found a number of cases where persons with disabilities fought for adoption rights, power of attorney and the ability to represent themselves in educational, legal and public manners (Nielsen, 2012).

The struggles mentioned above illustrate just how powerful this discourse is within our society. It permeates every aspect of the idea of disability and any counter narrative, discourse and belief is automatically pushed aside by this monologue. Further, the biomedical discourse is seen by most as fact. Within one of the interviews, a

participant shared, ". . . of course I can't do that [play piano], I can't see the damn music . . . I don't have the memory or the desire anymore. When I lost my eyes, I lost my music" (18: P4S3). For many, this discourse is obvious and literal, circulating throughout U.S. culture at large as a discursive template and is the basis for how many people construct the meaning of disability (Baxter, 2011). In Baxter's text, she situates relationship specific discourses that act as discursive templates. In this case, the biomedical discourse of disability acts as a discursive template for how our culture understands disability. A discursive template informs and is constructed from a cultural group's methods of communication, social practices and constructions of power (Fairhurst, 2007; Parker, 2015). This construct is often viewed as apolitical, in that the fact of disability is that a person is prevented from being able to do some aspect of everyday life.

The biomedical discourse of disability informs us that having a disability is a struggle for those who experience it (Darling, 2013). More accurately, having a disability can cause persons affected to be in a constant state of struggle. This is often echoed in our own language, and in one case, an example put forward by a participant of this study. "It isn't all bad, you know. I get some pretty sweet parking now, and when I was in high school, I got to ride the struggle bus. I get to be late and nobody cares" (07: P2S7).

Another participant shared,

At first, it was really hard. You know, people would be uncomfortable talking to me. I couldn't see them, but I know they were staring at me. From a distance, I look normal you know . . . but when you're up close you know, my eyes, they don't look right (17: P2S3).

In this space, we can see people use the idea of struggle differently, but each ties directly to how others view persons with disabilities.

Exploring the tenets of the biomedical discourse. To illustrate the biomedical discourse of disability, let's explore how each tenet is constructed through examples of the actual text and previous research where applicable. This should help illustrate what I found during this project and help frame the role of language in constructing the meaning-making that individuals went through in their choice of sharing their stories. In some cases, larger cultural scripts are called upon to help illustrate the gravity of how persons with newly acquired disabilities talk about their disability (and their experiences in making sense of having a disability). The first tenet is broken into two parts. First, the aspect of the undesirable trait and second, the solo experience.

Tenet one, part one: The undesirable trait. The first tenet of the biomedical discourse of disability is that having a disability is an undesirable trait that some people possess. More specifically, having a disability can range from being a condition, diagnosis or state of being that is unwanted, unplanned and not desirable to the individual affected (Darling, 2013; Shildrick, 2009). This tenet emerged from every single participant in this study. During the interview, participants were asked to put their life story together by creating chapters. Each individual framed their chapters differently, but each identified a time before their disability and a time after their disability.

Some labeled it as their "new life" or "a new beginning" while, one participant ominously labeled the change as "the incident" (07: P1S1). A major theme that informed this tenet was surprise in having a disability in their "new life."

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In high school, I was an athlete. A swimmer. . . I was good too. I was training for

the Olympics . . . I had a scholarship to college and everything . . . then one day it

was over. I got out of bed and I took a step and my thigh bone went through my

hip. It was over. And you know, it made sense. Earlier as a kid, I would get sick,

but not sick like a cold or sick with a flu, I just got sick. I would feel crummy and

I could never explain why. . . .. It turns out it was RA. My body was fighting itself.

And I finally had my answers (06: P2S3).

In another example, from the low point question of second section of the

interview protocol, a young man who went blind after his retina detached shares,

It was crazy man, one morning I was seeing, the next I wasn't . . . I mean it wasn't

that quick, but it kind of was. My vision was getting bad and I was having these

headaches and I couldn't explain why. I went from kind of seeing, to not having

that ability at all. If I could explain it better I would, but it was totally not what I

was expecting (17: P2S2).

In both examples, participants shared their surprise and the fact that their acquisition was

not a planned or desirable outcome. There stories are not unique as each participant

shared how they went from able-bodied to disabled in a specific moment.

These examples tie into the first tenet by illustrating the shock and uncertainty

that emerges from acquiring a physical disability. In the first example, the woman

recalled the loss she experienced when her thigh bone penetrated her hip. More

specifically, she prefaced the story with who she was prior to the acquisition of disability

and was able to use her surprise in her diagnosis to explain prior instances of illness. In

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the second example, the participant uses very direct and literal words to tell the story of being able-bodied and seeing in one moment two not being able to see. In this space, her use of literal language and unexpectedness calls forward this tenet.

Another participant framed it differently, as they were unable to speak to the actual event, but the after-moment when they realized what had happened. This individual suffered a traumatic brain injury (TBI) and was unaware of what had happened for weeks, as they awoke from a coma, and pieced together what they could through their confusion. I have replaced many of the verbal fillers with ellipsis in the following excerpt:

> . . . the low point of my story . . . was probably when I really understood what
> happened. . .. My sister told me I fell. I don't remember that . . . to be honest, I
> don't remember much . . . I sort of just came back and at first . . . I couldn't talk
> . . . I couldn't walk, I mean I still can't really, but you know . . . it sucked. I would
> lie there and you know, just stare up at the ceiling. . .. I could hear people and see
> them, but I didn't really know them, but I did and you know . . . it was a . . . it was
> a hard time. I remember my mom crying . . . and my sister she was great you
> know . . . but I could see that something bad happened . . . and at first it was like I
> was watching it happen . . . like to someone else . . . and then I could tell that it
> wasn't someone else . . . it was me (03: P2S6).

The participant went on to describe the event that created his disability. Some of the story has been filled in by the participant's sister in the weeks that followed his accident:

I was hanging out on the deck . . . it was just a normal day. My sister and I were

talking about something . . . and I was laughing. She said she left to let the dog

out . . . but I don't remember that. . . I just remember laughing . . . and then

waking up two weeks later . . . it was a trip man . . . like time travel you know?

. . . except when I woke up . . . my body and shit didn't work (03: P2S6)

In this example, the participant articulated both the aspect of it being undesirable and

unwanted. A major theme of this project was that each and every person who participated

can recall the events surrounding their acquisition of disability as one steeped in surprise.

These examples illustrate the tenet of the undesirable trait. In the example, the

young man suffered a traumatic brain injury by falling backwards off of his deck and

woke up in a hospital bed, confused and without the ability to communicate. His choice

in using words like hard or 'it sucked' call forward the idea that having a disability is

difficult and unwanted. Whether through surprise or frustration, in these moments, the

participant was able to employ the first tenet of the biomedical discourse of disability.

Tenet one, part two: The solo experience. The second part of this tenet is that

only some people possess this trait. This was often illustrated as being alone in the

experience. Not alone in the recovery or rehabilitation, but being the only person to really

understand the experience. In coping research, Trehane (1990) argues that when an

individual suffers a serious illness, acquires a disability or experiences a traumatic event,

they alone have to come to terms with the experience and often do so more quickly than

those they are connected to. Further, persons who suffer a life-changing event can cope

more with the changes to their life, while those around them often report feeling helpless

or frustrated in their role as an observer. If you go back and re-read some of the exemplars already, you will notice how some individuals made comments that articulated that either I should know what they are talking about, or that they struggled to articulate the lack of experience, desire or ability as a placeholder for those who cannot understand what that loss actually feels like. Throughout the interviews, participants were implicit and explicit in this area.

> One example comes from a young man who had a stroke at the age of 27. He stated:
> It was F-ing crazy. Man, you know, I could feel my brain just you know, stomping around inside my head. I was like seeing colors, it was like a bad trip and you know, I have never tripped before. But my mind was just letting go. I remember trying to talk my girl and she kept making these faces and these sounds, but I don't know man. I couldn't tell what was going on (08: P2S7).

He further articulates the experience of the stroke, but then we get to:

> You know it took over a year for me to get my voice back. I mean, I could talk, but the words they didn't come out right. So when I could talk, I mean really talk, nobody could relate to what I was saying. So, so let me tell you this, I remember I would say this [these] words, my ma showed me a video of me doing it, I would say 'bear apple tree' and in my mind, I couldn't figure out why they didn't understand . . . and what I thought I was saying was, why are you helping me? The words they got jumbled and as much as I try and explain it, no one really gets it (08: P2S7).

This example supports the second part of the first tenet of the biomedical discourse of disability as the participant can directly identify the lack of understanding of his experiences. In his example, after having a stroke he struggled with communication. His frustration in trying to understand why others could not understand him displayed that he alone, was implicated by the disability. The act of his mother showing him the video also displays a disconnect between experiencing the disability first hand and being an active observer.

> Another participant, a young woman who went blind during college shares,
> I know it sounds crazy, but I remember seeing, but it's not something that I can feel anymore. Like I have the memory, but you know, when I try and explain it . . . like not being able to see, I can't explain it because I don't see black. I just don't see (02: P2S8).

This experience was shared during her turning point narrative as coming to terms with being blind. In this example, the participant uses a memory of trying to explain the experience of being blind, and she invokes two times, before she lost her sight and afterwards. The inability to articulate the experience of having lost the ability to do something is not uncommon, but in this space, it is not an experience that people can mimic. In her words, she does not see black, she just does not see. This is not a sharable experience. The following experience echoes the same idea,

> You know, I get asked what it's like a lot. So I ask people, 'what's it like to fly? I mean, to like jump up in the air and just fly? You don't know? That's what it's like, not to see (21: P2S8).

The idea of being alone is not literal, but in this tenet is manifested by how individuals talk about how others understand them. Not every participant had a story like the ones mentioned above, but those who shared were able to explain that although they have people in their lives, they were alone in understanding the actual experience of having a disability.

Tenet two: Value and ability. The second tenet of the biomedical discourse of disability is that a person's value is intimately tied to their abilities. People with lesser amounts of ability are valued as less. Specifically, those with visible, physical disabilities are less valuable and less socially desirable. This tenet is tied to the legal definition of disability and illustrated through the experiences of persons with moderate to severe physical disabilities (Rufo and Hyde; 2000; Shildrick, 2002). This tenet is illustrated in a number of ways by the participants in this study.

The manifestation of this tenet comes in the form of how each participant talked about uncomfortable or negative interactions with other individuals. It important to note that these interactions may or may not have actually been negative, but the perception of the person with a disability specifically read the interaction to be as such. This tenet also manfiests when persons report being told they are limited because of their disability. This may include not being able to perform an activity, to not having the actual physical ability to perform the task in a manner that *is* the expected way to complete a task. In that space, their language and how they told the story is the space that this tenet is supported and the following examples reflect the boundaries of this principle.

One participant, a young man who was in a car accident that left him a quadriplegic, shares a low point for him when he tried going back to school.

Like I told you, I was 20 when I got hurt. You know with all the rehab and the bullshit, I lost a year of my life. I wanted to do something and I was going to college, you know I was going to uh . . . [redacted] Community college. It was just down the street. I had taken some classes, and I figured, I could do something . . . I remember my first day there. I walked into the classroom and all I saw were desks. I can't sit at a desk you know. The teacher, she was nice, but she didn't know what to do and I just remember everybody lookin' at me. They were sad. They pitied me (07: P4S2).

The previous narrative calls attention to how the participant's body, specifically his disabled body, sitting in an electric wheelchair changed the dynamic of the classroom space. He completed the story by stating that this class was the last one he attended. The ability to recognize or internalize the perception of pity in this space speaks to the second tenet of the biomedical discourse of disability. Specifically, he finds his value challenged as everyone looked at him and that his teacher had no idea what to do with him reflects how he perceives his value. Many participants reported that they had similar experiences in which people were either uncomfortable or uneasy in their presence. Research supports that persons with disabilities are often treated with awkwardness as their bodies do not match those around them (Shildrick, 2002).

Another participant, one who suffered a traumatic brain injury, shared a low point in her life that draws attention to the weight of this tenet.

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I was working with my PT. My dad was there and my little brother too. He was

always trying to come and help. We were working on the mat when Jeff started

talking about the future. You see, my injury left me with a couple deficiencies. I

can't close my left hand and my eye sight isn't great anymore. Jeff was talking

about work and what I wanted to be . . . I told him that I really wanted to be a

physical therapist. My dad snorted and quickly covered it up. I know that it wasn't

intentional, but I could tell, you know, in that moment he thought, like, I couldn't

do it and stuff. It hurt my feelings. It still hurts and . . . you know, why couldn't I?

(19: P2S7).

The young woman in this example explicitly recalled a moment where her value was tied

to her abilities. Her desire to pursue a career as a physical therapist was not a realistic

dream to her father. In that space, her father had judged her abilities and did not see them

matching with the perception of what he believed were necessary to conduct the job. This

directly supports the tenet that value and ability are tied intimately together.

Another participant, a young man who lost both of his legs in a car accident

shared a major turning point in his life.

I remember getting fitted for my legs. It supposed to be a good day. I had spent

the past 4.5 months in a wheelchair, my stumps were healed and we had begun

stretching the skin so that I could maybe start working on prosthetics. My brother

was there that day and he we were joking about that scene from Forrest Gump and

that guy, what was his name? . . . Lieutenant Dan I think. Well we were joking

about how I was going to ditch the legs and grow my hair out and work on a

'shrimpin' boat. My brother made a comment that I will never forget. You see. He became very serious and said to me, 'Eric, you're not serious, right? You can't work on a boat. You can't work outside. It's not safe. You should just go to school or something. Work inside, get a desk job.' Well, you know what? That - that pissed me off. I had always been an outdoors guy, you know, I didn't understand right away what he was trying to say. Right then and there, I felt like, you know, he just saw his poor legless brother you know? I was just like, I don't know. I was mad (14: P2S3).

Within a very similar space as the previous example, the participant identified a moment in which they experienced having their value associated to their disability. Eric was not serious about working about a shrimping vessel, but his brother used that to urge Eric into a different direction. Specifically, a direction where his disability would not be a hindrance or burden to positive and productive work. This supports the second tenet and speaks to a larger cultural script that promotes that a person's work should be productive. Additionally, a young woman who lost her sight shared,

I was crossing the street, and this guy came up and just grabbed my arm. I asked him to stop, but he just insisted on helping me across the street . . . you see, the problem was, he brought me to the side where I couldn't cross and all of a sudden, I wasn't sure where I was and it's not like I can see the traffic company. He totally, you know, put me in this position . . . he saw this blind girl walking and thought, 'I'm going to do my nice deed for the day' (02: P2S3).

In these examples, participants identified that their value or to frame it in another way, how others viewed them, was intimately tied to their physical bodies. In the first example, the young woman's perception of her father's reaction to her desire to be a physical therapist demonstrated a link between her abilities and her father's outlook on her future. Additionally, the following example also illustrated how a person's body can influence their potential future with the brother's sudden change in tone and topic.

Finally, the last participant spoke to a topic that has been explored communicatively and that is unwanted or unsolicited help (Soulee & Roloff, 2000). This participant was forcibly 'helped' when she was taken by her arm to cross to the wrong side of the street, by an able-bodied person who assumed that because of her cane, that she needed help.

Although not in the form of full thoughts or stories, many participants reported moments where people would frown at them, or say things like, "I am proud of you" or "you make it look so easy . . ." which implies that living life with a disability is going above and beyond the idea of just living your life. One woman equated this experience as, "being congratulated for being normal" (16: P2S7). Other participants reported feeling moments where people would stare at their chairs, or bodies, and sometimes faces.

One participant noted that her physical education teacher would find ways to compliment her physical prowess and dexterity, even when it was clear that she had clearly failed at a task.

Like, I don't get why he would do that, you know? At first, I thought he was like, making fun of me. I remember one afternoon specifically where we were jumping

rope and I just looked at him and I looked at my braces. There was no way this

was happening and so he laid the jump rope down and had me step back and

forth, over it. I felt humiliated and he kept telling me that I was doing great (06:

P2S5).

Another person spoke about how a person at her church insist on still praying for her to

be healed.

You know, I don't like going to church anymore. People still come up and look

me up and down, and say they are going to pray for me. I know they are just

trying to be nice, but what are they praying for? It's not like my RA is just going

to, you know, miraculously heal itself (16: P4S2).

In both examples, participants evoked the second tenet of the biomedical discourse of

disability. In the first example, the young woman recalled a moment where she felt

humiliated because the teacher created a high level of saliency to her disability. Her recall

of the event highlighted that the teacher, who for all intents and purposes probably

thought he was doing well, created a space where she felt less valuable (normal) than the

other children. In the second example, another participant called out the experienced

oddity of being prayed for when what is being prayed for is not something that she

believed could or should be prayed for. The act of praying for a person's disability echoes

that they are being valued less than other able-bodied folks.

Through the exemplars used above, this language and experience reflect the

notion that having a disability is not only a negative, unwanted state of being (as

articulated in the first tenet), but also one that creates a level of undesired-ness from the

person. Furthermore, this type of interaction is constructed in a manner that positions the person with a disability in a negative relationship to everyone else. Calling forth differences, creating increased saliency of the disability and praying for someone because they are disabled all communicate the messages mentioned above.

Another example comes from a participant who shared an anecdote about how a potential dating partner was repulsed by his prosthetic.

> [laughter] . . . so, you know, I was hanging out, and it was close to bar time when this girl, you know this girl she sat down and started chatting me up. I was sitting on a stool, a little drunk, probably a little charming and you know, she is laughing and we're having a good time. I turned my body towards her and she saw my leg, well my prosthetic and her eyes went wide and I thought she was going to fall off the stool. She quickly ended the conversation and I could see her back with her girlfriends and they were all peeking at me, like I was in the zoo, you know? (14: P2S6).

This anecdote illustrates how having a physically different body, specifically one marked with a disability is read by others. In this exemplar, we see that a woman was turned off by the presence of a prosthetic metal leg. This further supports the construction of the second tenet in that a person with a physically visible disability is valued less. Her leaving the interaction and 'peeking' at the participant as if he were a spectacle promotes the idea that the difference lowered his value to her after the revelation of a missing leg(s).

Tenet three: Disability and Stigma. The third tenet of the biomedical discourse of disability is intimately intertwined with the concept of stigma. Introduced by Goffman (1963), stigma or more specifically the experience of stigma is the feeling of abnormalcy in Being that a person undergoes when their identity is marked as different, undesirable or unwanted. Stigma is positioned within social intercourse, daily interactions and communicative events. Having a disability, specifically a physical disability marks an individual with stigma, and for those who have a visible, physical disability creates a socially constructed stain on any communicative events that they may encounter (Mitchell, 2015).

Stigma is categorized and typified by three traits. (1) Physical (external) differences that are identified as socially undesirable. (2) Deviating from expected norms through traits associated to persons (i.e. productivity of persons with disabilities); (3) Tribal or collective stigmas which separate a specific trait from the norm (able-bodied vs. disabled). This tenet emerges in our language as we not only construct disability in a negative relationship to ability, but in the language used to articulate a person's ability.

Stigma trait one: Physical differences that are identifiable are socially undesirable. One participant shared during their low point that they couldn't foresee being able to do the same types of activities they did before. Even in a space where assistive technology exists. "I know that I can still dance, but you know, it's not the same. It's not that easy" (11: P3S2). Or as another participant shared,

I had to learn to except that things aren't the same anymore. I mean, I can't just

run off into the woods anymore. I can't even get myself into bed, so I know I

can't just, you know, run off for a weekend (07: P2S2).

In these examples, participants identified through language the limits they have,

regardless of what they could actually do, construct their understanding as something

they could not do. The previous two exemplars implicate the role of stigma in their

communication of what they can and cannot do. In the first example, the lack of wanting

to dance as it is not the same echoes the fact that the physical performance of an act that

differs from the norm or expected performance is not socially desirable. The experience

is also labeled as not being the same and not being easy. These statements reflect a

negative perception of what used to be a simple act.

Struggle frames this tenet in relation to stigma. Whether self-imposed or spoken

by others, participants were able to illustrate stories that called upon this discourse as self-

defining/self-limiting. A middle-aged man with fibro myalgia states during his wisdom

event,

I came to peace when I learned my . . . limits. I know that I don't look disabled,

and sometimes this causes issues . . . so . . . this one time I remember getting out

of my car. I parked in the handicap spot at Target and I started walking in. This

lady stopped me before I got to the door and began to lecture me on why I was

using that space. I looked fine. She didn't know, you know? She had no idea what

I suffer from, and it wasn't until she stopped me that she realized that maybe there

was something wrong with me . . . in the beginning, this would have made me

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really uncomfortable, but now, I just try to explain. Sometimes people believe, sometimes people don't, you know? . . . at that time, I couldn't walk very well and my feet really hurt, what should I do, you know (09: P2S7).

This is a fundamentally interesting example of the first trait of stigma. The participant shared a moment in which his body was read to not match the expectations of the woman who called him out for not being disabled enough. He further explains that this is not an uncommon experience for him and that he has to justify how stigma informs how people view him and his invisibly disabled body.

Another participant references the time he was on campus. Part of this narrative was shared earlier in the chapter, but he revisited his first day of class.

I was struggling that day. Trying to get through a busy hallway is tough, especially with this thing [points at electric wheelchair]. I remember people making extra wide spaces for me and at least a dozen people asking me if I needed any help. I remember one guy actually started to walk in front of me, saying loudly, 'let the man through, he gots places to be' . . . and people would just look at me, they pitied me. Hell. I pitied me (07: P4S4).

These examples illustrate the role of the physical body as a location for stigma. In these spaces, participants chose to use language to illustrate how their differences differed from those around them. With Goffman's construction of stigma, specifically social stigma, we are able to see how these stories unfold and demonstrate the biomedical discourse of disability.

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Stigma trait two: Deviating from the norm. The second trait of stigma centers around characteristics that we associate as negative as they apply to different persons. This trait was constructed when participants would share the assumptions people made about them. In these stories and statements, participants identified moments that stood out against how they saw themselves. Earlier in the chapter, an example was used when a young woman shared that she might want to go into physical therapy and her father scoffed. Her surprise in this moment is a great example of how her father's perception of her differed from how she saw herself.

Another example comes in a series of comments that many participants made throughout the interview process. All of the exemplars to follow come the third section of the interview protocol, specifically the prompt that asked participants to speak towards how they saw their futures. Participants would preface or pre-emptively make a statement like, "despite what＿＿ thinks, I am going to do＿＿." A specific example comes from a woman who has late on-set juvenile rheumatoid arthritis. "Doctor's be damned. I am too stubborn and too frustrated to not go on this trip [in reference to attending San Diego Comic Con]" (04: P2S3). While another participant stated, "I was determined to dance at my wedding and not have to hold onto this damn cane" (13: P3S2). These types of statements speak to the second axiom of social stigma. While their attributes may visibly carry a negative message within a larger social group, the way they see themselves, communicate about their position is in direct opposition to this tenet.

The third trait of stigma emerges when participants spoke about how people who treat them based on their labeled disability. These stories and examples primarily came

out of the third section of the interview protocol, specifically the final prompt, "life project." Participants were asked if they had a life project, and literally every participant had plans for a book, journal or blog that would de-mystify their experiences and answer questions that people seem to always ask them.

One participant, a young woman who developed POTS said,

> I am just going to write a book. I mean people should know, you know, what it's like. I mean people see me, with my hair, and my make-up. Riding that short bus and they think that I am just gaming the system. I want them to know that not all disabilities look the same (05: P3S3).

Later in the same interview, this woman stated, "It's just about knowledge you know. I mean I talked about the book I am writing, but I just want people to understand and really get what it's like, you know?" (05:P3S3).

> Another participant, a young man who lost his legs in an accident said,
> You know, I started a blog once, it was nice way for me to just get my anger out and talk to myself about you know, the frustration. Like, I am living my life, and I can do it, but fuck man, sometimes I just want to scream at the stupid shit people say to me. I mean, maybe I will take that blog someday and make it public, or publish it or something. Just so people can read instead of always asking or just staring, that would be nice (14: P3S3).

In these examples, both participants articulated the need to alleviate the social stigmas that work against them. The first participant used specific language to articulate her desire to share her experiences so that other people would understand her. The second

participant used more direct language to argue that his blog could be used to just educate and stop others from asking.

Overall, the third tenet of biomedical discourse of disability is being driven by stigma, specifically social stigma. As participants voiced their experiences, different aspects of stigma are being called forward and given weight. In some cases, this weight was self-imposed, while others identified it through the actions of others.

In addition to the three major tenets of the biomedical discourse of disability, two ontological assumptions exist. As presented earlier, the biomedical discourse of disability is the dominant discourse. It permeates the discourse of disability so thoroughly, that everything relating to disability is juxtaposed with this discourse. The first ontological assumption of this discourse is that the language surrounding disability is apolitical. This means that how our culture makes sense of the idea of disability and specifically the biomedical definition of disability is housed in fact. People believe that having a disability is both undesirable and unwanted. Through the above used exemplars, we can see how language, specifically disability-related language can be seen as fact. The second minor assumption of the biomedical discourse of disability is that having a disability is harder than not having a disability. Throughout all of the interviews, participants identified low moments, moments of struggle and moments of hardship by evoking the cause to being their disability. This feeds into the monologue of the biomedical discourse of disability.

The Disability Discourse of Normalcy: Narrative Experiences of Persons with a Newly Acquired Disability

The biomedical discourse of disability positions the idea of having a disability as abnormal, unwanted, undesirable and difficult. This is the dominant discourse within our U.S. Culture, and really the world (Shildrick, 2002; Shildrick, 2009). The second primary discourse found in this study pushes against this discourse by directly challenging the notion of disability as being abnormal. Although this discourse exists in opposition, it would be irresponsible to not label this discourse as being juxtaposed. This distinction is important as the examples of the disability discourse of normalcy is often found interwoven with the biomedical discourse of disability.

The disability discourse of normalcy is a system of meaning that normalizes the concept of disability. Unlike the biomedical discourse of disability, the disability of discourse of normalcy positions ability and disability within the same space. Thompson and Braithwaite (2000) argued that one in two men and one in three men will experience disability at some point in their life and according to the US Census, currently as many as one in five Americans also experience disability (U.S. Census, 2004). This inevitability, whether from accident, to illness or to age, disability is a common enough occurrence that this discourse finds itself footing.

The disability discourse of normalcy is constructed and centered on language by two specific discourses: The socio-linguistic discourse of disability and the biopolitical discourse of disability. To continue this chapter, I will start by laying out the major tenets of the socio-linguistic discourse of disability. Throughout this space, I will use exemplars

to illustrate the subtleties and differences to the biopolitical discourse of disability. Afterwards, I will identify the importance in the linguistic differences in the socio-linguistic and biopolitical discourses of disability that will lay the foundation for the following chapter.

Socio-Linguistic Discourse of Disability

The socio-linguistic discourse of disability is constructed through participant stories where they were reflexive of their own positionality and their own experiences. This discourse is constructed of two major tenets and two ontological assumptions. The first tenet normalizes disability, to be more accurate, shifts disability out of the binary relationship with ability and does so through normalized, abled language. The second tenet of the socio-linguistic discourse of disability is that it is distinct within our culture and how we construct meaning in relation to a shared understanding (i.e. Biomedical discourse of disability). This discourse is concerned with centering the individual and has two ontological assumptions. (1) Ability and normalcy are present in every act that we do. Due to the inherent embodied nature of experience, having a disability is political. The second assumption is that varying degrees of ability is inherent to human experience. (2) Ability exists on a spectrum of experience and is an inevitable aspect of human life. The following exemplars will illustrate and support the various tenets and assumptions within this discourse.

Throughout all the interviews, participants would reflect or call forward the discourse of normalcy in their story telling. From subtle choices in language to more direct, explicit stories. One example of the latter comes from a young woman who lost her sight during college. This narrative is a continuation from an earlier exemplar in which she shared how a man ushered her across the street and put her on the wrong side of the road.

You know, I know the guy was trying to help. Obviously I am blind. I have a

cane, I am walking on a semi-busy street, there was sidewalk construction, some

obstacles, and I don't think he understood that he was actually making my life

hard. I mean, if he would have left me alone, I would have been just fine. I can

see where I was going because I walk the same path every day (02: P2S3).

She further explained "I know he meant well. I really do, but there is irony in the fact that

the blind girl could see what he was doing before he could." In this example, the

participant purposefully chose to use the word see in two different contexts, both of

which evoke normalizing abled language. This subtle use of language invokes

normalcy by employing specific language that implicates able-ness. Specifically, when

she says, "I can see where I was going . . .", the participant engages in normalizing

communication, which is fundamental to the sociolinguistic discourse of disability. In the

context of the full sentence, she also explains how her "seeing" where she is going

because she walks the same path everyday speaks to how people who are blind navigate

space. Which is different when she has been somewhere before and when she has to

experience. Another example comes from the young man who lost both his legs in a car

accident.

So, I remember this one time, I was walking down the street, smoking a cigarette

and talking with my neighbor. I can't remember where we were going, but my

wheel got stuck on the curb. I mean, I was really stuck (01: P4S3).

In this example, the participant used the phrase walking as a normalizing language to

speak to him traveling from one point to another in his wheelchair. This choice in

language illustrates the normalcy in an everyday activity. In this example, similarly to the example with the woman who is blind – seeing, this example invoked normalcy by using the phrase "walking" to reference moving with his chair. We see this in the story as he stated his 'wheel got stuck on the curb.' The juxtaposition of abled language with disabled experience is fundamental to the sociolinguistic discourse of disability as it seeks to normalize disability through speech.

Additionally, one participant shared,

I know that they were just watching, wondering – am I going to come in, or am I just going to walk away. It was sort of fun to watch them watch me. I mean, they don't see a lot of guys apparently in chairs, you know (01: P3S2).

This example also utilizes walk as a method of normalizing an action. In all of these examples, there is an obvious push for normalization. When participants invoke abled language to describe activities that are obviously different or disconnected from their literal actions, meaning is created that communicates an experience that is the same or similar enough to abled-experiences that normalcy is created. To better understand how this discourse emerges in talk, less obvious or less salient examples are needed.

One participant, a middle aged woman with late on-set juvenile rheumatoid arthritis speaks to a wisdom event that she experienced at her physical therapy appointment.

This probably occurred like, three or four months after my surgery. I had taken a step and pushed my thigh bone through my hip and you know, it wasn't an easy thing to experience or try and recover from . . . I was walking out of the gym and I

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saw this kid sitting there staring at me. She was on the mat with her therapist . . . I

know what she was thinking . . . and I wanted to be supportive and so I said to her

. . . I said, you can do this. If I can do this, you can do this. You got this (06:

P3S2).

This story references the participants experience of rehabilitation. This story was

set in a rehabilitation office in a large, rocky mountain facility. The participant used her

own body and her own experience to show that the younger child that lots of types of

people experience rehabilitation and if she could in fact get through it, so could they.

Another example that illustrates the subtleness of normalization and abled

language comes from a young man who had a traumatic brain injury. This also reflects

the second tenet of the socio-linguistic discourse of disability. The story takes place

inside of a coffee shop in a small, Midwestern town.

It was kind of crazy. This was a major turning point for me, this helped me realize

that I could get through all of this you know? I was standing inside a Starbucks

when this lady collapsed. It was sort of busy, maybe like five or ten people sitting

at a variety of tables. Nobody moved. They all just kind of stared and watched.

Some were pulling out their phones, but nobody was getting up. I mean, I used to

be an EMT, so this kind of stuff didn't spook me. I mean, as soon as I figured

nobody was going to get up, I hobbled over and got on the ground. She was

conscious, but clearly a little, um, a little out of it, so I you know, kept her calm

and waited with her (20: P2S3).

This example normalizes both the action he took, and the physical behaviors described. His use of hobbled shifts the word from a negative action to a normalized one. This type of choice when using language also constructs disability, in that space, as an everyday occurrence.

For these exemplars to make sense within the context of the discourse, two primary assumptions need to be understood. First, ability is present in every aspect of what we do. Our language reflects this when we say phrases like, "It is what it is," or "that's life." This implicates the idea that having a disability is inherently political. Meaning, ability and disability is embodied both in physical form and communication. To reiterate an earlier claim, ability and disability are not in a binary relationship, but rather parts of the same whole.

This assumption can be embodied in the following exemplars. First, a young man talks about life after being in a serious car accident that left him a quadriplegic. He states, "I remember my life before and I remember waking up after. I know that my body does not work in the same way, but I am still the same person. I don't feel really any different" (07: P3S1) This example introduces the idea of disability as being normal. Another participant, a younger woman who had a stroke, while at work states, "I remember the stroke happening, and I remember everything. You know, it wasn't bad or as bad as it could have been and when I woke up, I just wanted to get back to my life" (13: P2S3).

In each of these examples, participants articulate the experience of having a disability as being normal. Coping research suggests that this occurs due to a person's need to make sense of a serious or tragic situation. More specifically, Trehane (1999)

argues that the person who experiences the change directly is more likely to normalize the reality faster and more efficiently than those around them. This notion occurs in the story of a young man who was left permanently injured after a fork lift accident. His story illustrates and connects normalcy from the perspective of the person with a disability, while remaining uncertain or non-normative to those around them.

Specifically, this participant mentions his daughter fussing over him as if she was his mother. This type of interaction reinforces how the construction of normalcy is different for the person who has the disability and those around them.

I remember standing next to the wall when the forklift turned around. I saw it coming and I knew it was going to hit me, but I couldn't move . . . there was not a lot of pain or anything, but I remember seeing the bones in my leg sticking out of my jeans. It was weird . . . and then some amount of time passed. I woke up one morning and my legs were on fire. My wife and daughter were there, and they just looked sad. At that moment, I was more worried about how we were going to survive than I was about what the long-term effects would be for me. You know, I just wanted to take care of them, and they were just worried about my legs. Fast forward almost three years, and really I am fine. I still use a cane, but I can work, and I can take care of them. My daughter, who is now seven, fusses over me still. It's like I have a mini-mother (12: P2S6).

The sociolinguistic discourse of disability makes up a large portion of the disability discourse of normalcy. The other discourse, which is the biopolitical discourse of disability seems very similar to the socio-linguistic discourse of disability, but differs in

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one specific aspect. Unlike the latter discourse, the biopolitical discourse of disability uses non-abled language to normalize disability.

Biopolitical Discourse of Disability

The biopolitical discourse of disability is loosely based on Foucault's notion of a dispositive (1978). For the purpose of this study, a dispositive consists of discursive identity policies that cause structural shifts within social relationships and self-representation. Foucault's dispositive can be understood as an apparatus that "consists of discursive, institutional and identity policies that structure social power relationships and form new ways of self-representation" (Waldschmidt, 2006). European disability scholars approach the concept of dispositive and disability from the stance of a subversive status which requires disability to create self-representation through non-normative means (Pfahl & Powell, 2014). In this space, the biopolitical discourse of disability revokes normalcy and invokes self-representation through non-abled or literal language. This resists against the abled construction of normalcy and complicates institutional and identity politics by challenging how we see disability. Further, the biopolitical discourse of disability is founded in normalizing disability through literal representations of experience to create new forms of self-representation (Waldschmidt, 2006).

Tenet one: Literal language. The first tenet of the biopolitical discourse of disability deals with normalizing disability through the use of literal language. One example comes from the young man who lost his legs in a car accident.

> You know, it's weird right, I was watching my nephew play soccer and the ball
> was coming at me and I jumped out of my chair to kick the ball back you know?

The problem was, I was a lot lower to the ground and my stump couldn't reach the

ball (14: P2S7).

In this example, we see the participant label a non-normative body part in context with

abled language to create non-abled language. He continues, "I remember just sitting on

the ground and my nephew just stared at me. Well, he really just stared at my stump." His

use of stump is a non-normative label for a body part that he has, yet most others do not.

This language becomes contextualized through the first part of the story with soccer and

trying to kick the ball, yet where he could have chosen leg or even foot, his use of the

word stump changes the construction of normal and creates a new method of self-

representation.

Another participant shared during a vivid adult memory a moment in which he

was celebrating with his friend, a successful outcome on a test. He shares,

It was finals week and my roommate was worried because he had stayed up all

night to study and needed this class to graduate. Our professor was cool, he said

he would grade the test right after class and my roommate asked if he could do his

first. So we waited in the hallway of Dr. Tan's office while he looked over the

test. After a few minutes, Dr. Tan came out with a smile on his face and my

roommate almost fell over . . . he was so happy. I remember yelling forearms.

Which to us was like a high five (08: P2S6).

This example clearly illustrates the participant calling forward the biopolitical

discourse of disability by literally explaining a moment in which his language did not

match the expected language. Normalizing a congratulatory action of bumping forearms

instead of slapping hands shifts and normalizes disability in a manner that is both literal and normal. This act creates a normalized method of self-representation of disability, while using non- abled language in an unexpected manner.

Another example of this tenet comes from a middle aged man with fibro myalgia. In his story, he shares,

> I was at Home Depot. My wife asked me to build her a shelf for the pantry and I was heading there to get the supplies I needed. That day was bad though, my body hurt and my hands were shaking badly. I couldn't stop the shaking and I remember having to ask to get a box of screws off the bottom shelf and I remember sort of spasm-ing as a gesture to the ones I needed because I couldn't get my hands to take the shape I wanted to (09: P2S6).

This example calls forward the normalcy in trying to point but using a spasm to gesture towards the item he needed. This use of language uses literal language to create a story that normalizes disability. Spasming a gesture, as mentioned in the story above is not normative, and forces the construction of a new construction of self-representation of disability.

In these examples, the switch in code was intentional and both participants consciously used different, literal language to normalize disability. Less obvious examples also existed within the stories shared by other participants. Two exemplars come from two participants who use wheelchairs to get around. First, a young man who lost the ability to walk after he contracted a disease that damaged his spinal cord. "My girlfriend and I went to a concert and if you've ever been on the floor of a Blink 182

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concert, it's crazy. I had to keep trying to maneuver my chair to get through the crowd"

(01: P2S6). The second participant shared a similar story when navigating a college

academic building hallway during passing time.

> I just had to get out of there you know. It was intense. I couldn't steer the chair all
>
> that well because my hands don't work that well. I kept bumping people with my
>
> foot and when I would turn, I would hit their feet. It was awful (07: P4S2).

While these exemplars embody the first tenet, they also begin to address the second tenet

of the biopolitical discourse of disability. In the first examples, non-abled, literal

language to tell their stories. This approach challenges normalcy through complicating

and creating new methods of disability self-representation by highlighting non-abled

language (i.e. my stump).

Tenet two: Practical language. The second tenet uses practical language where

non-abled language is not highlighted or used explicitly. In the previous examples, stump

and slapping forearms were used. In the previous example, the participant implicated his

chair as an act of non-abled, literal – yet practical language. The following examples will

shift focus away from physical bodies to adaptive equipment. In this space, they also use

practical language to communicate literal experiences.

The final exemplar comes from a younger man who suffered a traumatic brain

injury after falling nearly ten feet off a roof.

> I remember being in rehab and I remember all these people would come in and
>
> out. I had no idea who anyone was, but there was this pretty lady who kept
>
> helping me. I was smitten. I tried talking, but my stutter was so bad that, I, um,

you know, tried to ask her out. There was no way she could have understood me.

She laughed and laughed, and I wasn't sure why . . . she hugged me and she was

crying . . . I later found out that she was my wife (15: P1S1).

The participant constructed in this story normalcy in his stuttering. In this story, which he

used as his turning point event, illustrates his stutter as being a normal part of

communication. In this example, by specifically choosing to use the word stutter, over

other phrases, he is constructing a new way to look at disability in a normative way. To

frame this in a manner that makes sense within the tenet, by using stutter practically, he is

creating a new space where disability is meant to be normal. Like the socio-linguistic

discourse of disability, the biopolitical discourse of disability frames having a disability

as political. Disability and ability are embodied through language and in each of these

exemplars, a contextual value of normalcy emerges.

Juxtaposition of the Biomedical Discourse of Disability and Disability Discourse of

Normalcy.

In the descriptions listed above, the differing discourses of disability appear to be,

but are not positioned against each other. This is mainly due to the nature of the

biomedical discourse of disability. This discourses acts as a monologue and permeates

virtually every communicative space from how people define and talk about disability,

the lexical rules in grammar to the way this identity is portrayed in popular culture. As

Bakhtin (1983) argues, a monologue is a single voice that silences other voices, the only

place the disability discourse of normalcy can exist is alongside.

In the exemplars used, examples emerge where participants evoked both discourses within the same utterance, paying recognition to the monologue, yet providing space for the disability discourse of normalcy. We should note, that in these moments, both discourses are presented in a manner that does not change the nature of the discourse (hybrid) , nor does it create something new (aesthetic moment), which Baxter argues can happen within the interplay of competing discourses.

Overall, this chapter illustrated the complexity of two distinct discourses of disability that are inherently connected to each other. First, the biomedical discourse of disability is the single, loudest and most prominent discourse of disability. We see that this discourse permeates every aspect of our social world and acts as a discursive template for disability that all other discourses must fit into. The second discourse, the disability discourse of normalcy is manifested in two distinct discourses: the socio-linguistic discourse of disability and the biopolitical discourse of disability. Both discourses are remarkably similar, with the biopolitical discourse differing in the type of language used when talking about disability. From this chapter, you should be able to see just how connected the socio-linguistic discourse is to the biopolitical discourse and how both construct the disability discourse of normalcy. Although, we could argue that this discourse is in opposition to the biomedical discourse, in reality is juxtaposed. We see moments within these stories where both discourses are present and not in opposition of each other. This notion will be thoroughly explored in the penultimate chapter of this project.

CHAPTER FIVE: DISCUSSION

Experiencing the stories that participants shared during the interview process of having a newly acquired physical disability provides a unique and rich insight into trying to understand the cultural and relational discourses that surround the concept of disability. Addressing the research question for this project, two primary discourses of disability were found using a discursive thematic analysis, the results show an interesting relationship between the biomedical discourse of disability and the disability discourse of normalcy. More specifically, the results demonstrate an interesting, albeit unique finding in that instead of discourses in opposition, the disability discourse of normalcy is juxtaposed to the biomedical discourse of disability. In the exemplars present within the previous chapter, there were many examples in which the biomedical discourse of disability and the disability discourse of normalcy were present within a single narrative. Here is an example:

> You know, it's weird right, I was watching my nephew play soccer and the ball
> was coming at me and I jumped out of my chair to kick the ball back you know?
> The problem was, I was a lot lower to the ground and my stump couldn't reach
> the ball (14: P2S7).

Within this excerpt, the participant – a young man who lost his legs in an accident employ both discourses (biomedical discourse of disability and the disability discourse of normalcy. In the way that he problematized his 'jumping' out of his chair and his inability to perform a task draw upon the biomedical discourse of disability, while his use

of able and non-abled language in 'jumped,' 'kick,' and 'stump' invoke the

sociolinguistic and biopolitical discourses of disability respectively. Let me provide an

additional example before I unpack the idea of juxtaposition. In the following example,

> I just had to get out of there you know. It was intense. I couldn't steer the chair all
>
> that well because my hands don't work that well. I kept bumping people with my
>
> foot and when I would turn, I would hit their feet. It was awful (07: P4S2).

There is a clearer illustration adducing the biomedical discourse of disability in his

identifications of intensity, his physical limitations and overall generalization that it was

an awful experience. Within the same narrative, the participant melds his chair as part of

his body, identifying his foot plate (the portion of his chair where his feet rest – the foot

plate protrudes further than his feet do while at rest) as his feet.

The use of juxtaposition in reference to the discourses described above are in their

meaning-making of disability. With the biomedical discourse of disability, a monologue

exists that is considered by most people to also be an objective truth. More accurately,

people construct the meaning of disability to be undesirable, unwanted and persons who

have disabilities to be less capable and less valuable. This construction is built upon

historical and legal constructs and what people observe on their own.

When a person has an acquired physical disability that is visible, they are unable

to hide that aspect of their identity. Others view that person based on their personal

experiences that relate to disability and draw upon how others' talk about members of the

disabled community. Others (able-bodied) construct meaning from what they see on

television, read about from their various news sources or listen to in their music, radio

and podcasts. This information rarely provides an accurate or holistic understanding of the lives of persons with disabilities and leads to a misinformed perception of what disability means. This perception in relation to the historic and legal constructs perpetuate what people know about disabilities. To more accurately speak, when the message surrounding disabilities is constructed to be negative in nature and is reinforced through multiple forms of communication, what should be a subjective truth is often conflated to be objective.

In the disability discourse of normalcy, a different lens is being used to construct the meaning-making process of disability. This viewpoint seeks to normalize the idea of disability through how we communicate about having a disability and specifically, the language used when talking about having a disability. In the examples presented through this project, the disability discourse of normalcy is juxtaposed with the biomedical discourse of disability in a manner that is not oppositional, but rather positioned with or existing within the same space.

In this chapter, I provide a synopsis of the results from the previous chapter. Next, I will unpack the relationship of the two discourses of disability. I will then explain the significance of these findings. After, I will present the practical applications of the information from this study. Last, I will wrap up this chapter by presenting the limitations present within the study and providing a theoretical framework that further studies may take to enhance our understanding of disability within interpersonal and relational communication.

What disability means?

The concept of disability, as constructed by the individuals who participated in this study invoked two primary discourses of disability. First, every participant called upon the biomedical discourse of disability.

The biomedical discourse of disability. This discourse is certainly the norm within the United States. It permeates many conversations surrounding ability and disability and constructs a space where the meaning of disability is negatively positioned to normalcy. Assumptions on lifestyle, ability and happiness are all tied to ability, just as productivity, competency and desire are tied to disability. In the example earlier, the young woman who had a traumatic brain injury shared the pain she felt when her father questioned her future by speaking of how he perceived her abilities and the boundaries constructed by her disability. Throughout the three tenets of the biomedical discourse of disability, disability is consistently positioned negatively against ability. This positioning creates a false binary.

Tenet one, part one: The undesirable trait. In the first tenet, having a disability is an unwanted condition, diagnosis or state of being that is unplanned and majorly impacts a persons' self. This argument is nonsensical as very few people wish /desire to acquire a disability. In fact, every year – new messages are created by healthcare professionals on the importance of performing certain tasks (eating, exercise, personal care) as a method of preventing disability.

Tenet one, part two: The solo experience. Persons with acquired disabilities report the experience of having a disability as unique, different and often unexplainable.

Exemplars described scenes where people tried to explain the experience of having a disability and found that they were unable to communicate effectively what they were going through. Some participants used metaphoric language to explain the experience, while others attempted to explain the phenomenon with literal language. In either case, the experience of disability is hard to share as there is no direct or effective method of creating empathy or a shared experience. The best example came from the exemplar with the participant who talked about not being able to see. They argued that unlike trying to understand by closing your eyes and seeing black, they just did not see. There was no darkness, there is just nothing. In this example, there is no way to recreate the experience for others to share. Using an eye covering to simulate blindness, wearing earplugs to recreate deafness or having someone sit in a wheelchair are not accurate representations of having that type of disability.

Tenet two: Value and ability. The second tenet of the biomedical discourse of disability dealt with assigning value to an individual based on their abilities. This tenet is steeped in history and United States culture. Nielsen (2012) traced the history of disability from the inception of our country and we have often associated disability with capability, competence and self-sufficiency. In McAdams (2000) redemption turn in his life story interview, he identifies our ability to produce as a key characteristic of United States culture and this tenet is built out of this belief. The existence of an accommodation is in direct support of the idea that if a person can do something in the same way as another, their value should be equal. The reality and what becomes complicated in this space is the social construction of what value means within different contexts. A good

example of this complication comes from the person who shared the story about his brother while he was being fitted for his new legs. His brother over-reacted and told him he should be looking for a desk job and he should not focus on running off and working on a shrimp boat in the southern United States. In that space, for that memory – the participant was able to experience how his brother associated his value as a productive member of society in relation to his abilities and as a result, his disability.

Tenet three: Stigma. The third tenet of the biomedical discourse of disability is driven and sustained by stigma. Stigma is housed in the cultural discourses that exist within our society. Specifically, the historical and social contexts that paint a picture of what having a disability is like and how impacts the self. Historically, persons with disabilities have been painted as need-dependent or reliant upon family and friends to help conduct daily tasks. Disability scholars have studied the dangers of stigma within the context of U.S. Culture (Darling, 2014); interpersonal relationships (Braithwaite, 1996; Soulee and Roloff, 2000); and within academic spaces (Hubbard, 2006; Trammell, 2009). Stigma becomes a driving force of this discourse as there is a significant amount of history permeates every message on disability that is constructed. In spaces where participants enacted other discourses of disability, they would often invoke aspects of stigma alongside their resistance to the biomedical discourse of disability.

The disability discourse of normalcy. The disability discourse of normalcy is the marginalized discourse(s) or meaning(s) of disability present within United State culture. The sociolinguistic discourse of disability positions abled-language as a mechanism of normalizing disability, while the biopolitical discourse of disability

positions non-abled language as a mechanism of creating new self-representation of disability. Each discourse provides a unique level of insight into the larger cultural narrative of disability, as it is constructed through the biomedical discourse of disability.

The sociolinguistic discourse. The sociolinguistic discourse is constructed from the belief that ability and disability are the same in that disability becomes a deviance from ability or in the context of this project, normalcy. This significance is founded in language and is embodied by participant's use of abled language to normalize their disability within a specific space. This discourse was identified through the analysis of stories shared by participants in the first portion of their interview.

The sociolinguistic discourse of disability posits that ability and disability exist on the same spectrum. Meaning, ability is a constructed idea that has arbitrarily stratified persons who may appear different or require assistance in performing tasks that others do not. This spectrum informs how we think, act and behave in the context of 'normal' or in other terms, 'able.'

Tenet one: Ability and normalcy are everywhere. The first tenet of this discourse becomes voiced by every person who has a disability and uses abled language in their everyday speech. For example, wheelchair users will turn phrases from "wheeling" to "walking," just as persons who are blind will turn "sensing" into "seeing." These turns complicate normalcy and linguistically shift the experience of disability away from a binary to a realm of experience. Normalization occurs both inherently and deliberatively for persons with acquired disabilities. In each case shared and in my own personal experiences, using literal language does not even occur cognitively as the

language becomes representative within the act, unless a high level of saliency exists surrounding having a disability. Bakhtin's (1984) construction of a speech act finds that messages are representative of intention and in this space, literal language is not privileged over figurative.

Tenet two: Ability is a spectrum. Ability exists on a spectrum and this idea is constructed a postmodernist perspective and positions meaning that is relatively constructed through societal and greater cultural discourses and is resistant to often taken for granted assertions or beliefs on what the state of reality should be. Baxter and Asbury (2014) further this understanding by situating the unstable nature of a critical postmodern perspective on discourses as an act of counter discursive resistance. Within this project, meaning is made in each space based on the participants, locations, lived experiences, past experiences, and cultural beliefs.

In this tenet, participants would normalize disability in a space, but not escape what Mitchell and Snyder (2009) argue to be the inescapable stain of disability. Meaning, that regardless of language, the disability is read and ascribed onto a body. What is written upon a disabled body carries the biomedical discourse of disability and almost 250 years of stigma created from what was culturally constructed in the time to be dependent and incapable. Baxter and Asbury (2014) continue the argument by citing the importance of a critical postmodernist approach to language by using Deetz (2001, p.7), the purpose of this project is to resist discursive closure and to "reclaim conflict" by claiming a space for 'lost voices' of resistance to dominant discourses. This project use of the disability discourses of normalcy enact a form of resistance/recognition and through

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both the sociolinguistic and biopolitical discourses of disability; Find space to recreate

representation and understanding that surround having a disability.

The biopolitical discourse of disability. The discourses of disability within this

project speak to the existence of a larger cultural narrative in which persons are expected

to be or do their lives within a specific set of socially acceptable rules that are constructed

from historical, legal and cultural precedence (Shildrick, 2009). The disability discourse

of normalcy further this understanding by position ableness/normalcy with disability as

inevitable and inherent aspects of the human experience. Human life is not broken into

autonomous and dependent, able and not able, but into life and no life. We find that

ability/normalcy exists upon a spectrum of experience and for some, their ability to

perform everyday tasks and functions may become more difficult than others.

The biopolitical discourse of disability is very similar to the sociolinguistic

discourse of disability. The variations lie in the language use. Unlike the abled language

evoked by participants enacting the sociolinguistic discourse of disability, the biopolitical

discourse of disability invokes non-abled language. This act is based loosely on

Foucault's notion of the dispositive. This idea positions marginalized ideals, phenomenon

or apparatuses as mechanisms of creation for new forms of self-representations.

The biopolitical discourse seeks to normalize ability and disability onto the same

spectrum, but rather than invoking abled language to construct normalcy, it purposely

uses non-abled language or literal language as a linguistic tool to create connection or

new self-representation of disability in a normal space. We can see this in participant's

stories when they don't use "walk" instead of "wheel or push" and "sense" instead of "see."

Tenet one: Language is literal. In the first tenet of the biopolitical discourse of disability, the use of language separates the biopolitical discourse from the sociolinguistic discourse of disability. In this space, participants would name body parts or acts that are normally performed in a space a certain way, and insert non-abled language to create the same affect. Whether a participant talked about kicking a ball with their stump, or congratulating a friend with a forearm rather than a hand, this tenet is illustrated using literal language.

Tenet two: Language is practical. The second tenet of the biopolitical discourse takes literal language and turns it practical. In these spaces, participants invoked non-abled language in a way that does not make sense to turn relative like in the sociolinguistic discourse of disability. An example comes from a man whose spasms and pain did not allow him to use his hand in a realistic fashion to point at his needs at the hardware store. Rather, the participant used his spasms to create and direct the person helping him. This shift in language normalizes the act of communicating and normalizes the disability alongside by constructing a meaning that is both practical and housed within a communicative space that made sense at the time.

In both aspects of the disability discourse of normalcy, disability is constructed through a critical postmodern approach to language. In this space, meaning is not stable and each and every encounter creates and recreates meaning. Where participants invoke the biomedical discourse of disability, they challenge the meaning of disability by

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juxtapositioning the disability discourse of normalcy. This becomes significant as these discourses have never been looked at together in the language or experiences of persons with disabilities.

This project is positioned within a post-modernist approach to critical theory. By focusing on language as the site for power, rather than the phenomenon, the data that was found and analyzed in this project consists of lived experiences of the participants and demonstrate the meaning-making of disability as an unstable space where taken for granted assumptions are constructed with discursively constructed representations that are different. These differences take shape through how participants told their stories.

Within the data, various discourses emerged to construct the meaning of disability through the everyday talk/narratives of the participants. What each person said varied, but different ideas carry different cultural weight. Additionally, each participant had to engage in a dialogic process in negotiating what stories to tell, how to tell them and how to remain representative of their positionality as they told their stories (Raggat, 2006). This process provides a unique insight into how individuals with newly acquired physical disability negotiate the meaning-making surrounding disability.

Why this is so important?

This project furthered the understanding of disability meaning-making in two different areas. This progress is significant in understanding the experiences of persons with newly acquired physical disabilities and can lend itself to exploring how monologues function within social constructs. Additionally, identifying external and relational factors that impact how individuals construct their understanding of having a

disability position the role of stories as a methodological tool in understanding non-familial relational identities. Further, by identifying disparate discourses of disability an argument is founded in learning more on the impact of disability has on identity construction and maintenance for all persons is made.

The first area of significance: The function of a monologue. This project explored the relationship between the biomedical discourse of disability and the disability discourse of normalcy. As mentioned earlier, these discourses are not necessarily in opposition of each other. More so, they exist in relation to each other and are often invoked differently as dictated by the individual, the communicative space and nature of the message. In many of the examples within this project, the biomedical discourse of disability was invoked within the same utterance of language as the disability discourses of normalcy. This becomes important as the biomedical discourse is a totalizing monologue.

In the seminal work, Voicing Relationships, Baxter (2011) argues that within everyday talk, discourses are often found to have different footing. More accurately, Baxter argues, while echoing Bakhtin (1986) that each interaction that is created is fluid and dynamic, unrepeatable and meaning is completely fluid. On a spectrum of idealized talk, monologue exists as a capstone opposite of idealized dialogue. In the presence of a monologue, all other meaning is erased by a totalizing discourse or held silent.

In Relational Dialectics Theory's new articulation (RDT 2.0), power is located in the way meaning is made from language. More accurately, Baxter argues that "power is conceptualized as the discursive ability to define social reality" (Baxter, 2011, p. 121).

With the biomedical discourse of disability, the social reality of disability is constructed as a monologue. This means that what we know and how we communicate as a larger cultural body is seen or assumed to be the truth. This belief becomes a discursive template that impacts how persons talk, think and act in accordance to disability and ability.

This project furthers our understanding of how monologues work and I believe, challenges the idea that all other discourses are silenced. In this space, any manifestation of a differing discourse is broken down and in a position that needs to exist alongside the monologue even to exist. Since different discourse do exist, are employed alongside and are not resistive, I argue that discursive monologues do not always function as a silencing mechanism towards other discourses, but rather present in a form that allowed multiple voices have to exist. In the exemplars from this study, the biomedical discourse was present alongside, intertwined, but not in opposition to the disability discourse of normalcy. There should be no doubt at this point on how encompassing the biomedical discourse of disability is within United States culture. This discourse literally permeates every aspect of our total lived experience. From a historical lens, Nielsen (2012) traced the role of disability and the perceptions of our society at the time. This analysis consistently framed disability as a negative attribute that carried a negative ascribed meaning throughout the entirety of United States history. From a cultural perspective, the existence of curb cuts, braille and elevators promote the difference between being able and disabled (Shildrick, 2009). The media paints having a disability as sensational and will often praise persons with disabilities for their accomplishments, despite their

challenges. Interpersonally, relational scholars and others have noted the challenges

presented by others when inquiring about romantic relationships, physical ability and

sexuality (Shakespeare, 1994; Lindermann, 2010). Shapiro (2014) argued that this is so

prevalent that the belief of having disability is so difficult, unwanted and quite a bit less

than the idealized state of being, that more than 1.3 million abortions occurred in one

year from mothers being told that their child would be born with some form of a physical

disability. These examples, although not exhaustive – demonstrate the depth of belief in

the biomedical discourse of disability.

The spaces that the disability discourse of disability, specifically the

sociolinguistic and the biopolitical discourses exist within challenges the silencing of

discourses. I believe that this project, at the very least – justifies the need to further

explore totalizing discourses and the construction/existence of centrifugal discourses as

they relate to meaning-making. This project recognized a number of exemplars in which

the biomedical discourse existed in relation with the disability discourse of normalcy and

within that space – constructed meaning that recognized the biomedical discourse of

disability and still constructed a different meaning or self-representation of disability.

The second area of significance: Stories, discourses and methodology. In this

project, participants were prompted with 22 scenarios in which they were asked to

explain or tell stories. Some of the story prompts turned into explanations as individual's

experience had not encompassed all the political or future based expectations. In this

space, participants enacted through story, discourses that have up until now been

theorized from a greater cultural narrative. This study identified and explored multiple

discourses within the same space from the perspective of the individual with a disability.

The choice in using participants with self-identified newly acquired physical

disabilities was purposeful as their scripts were not finalized and in some cases not yet

written when they talk about what it means to have a disability and what disability means

to them. By letting the discourses emerge in the context of stories, external and relational

factors that influence meaning-making are identified. The methodology of data collection

celebrates McAdams' construction of identity through narratives and explore and further

identify the discourses of disability in both a cultural and relational space. He argues that

identity is not found in personality traits, behavior dispositions or complexities and not

our political and religious values. He argues that our identity lies within our stories. In

this area of significance, cultural and relationally constructed discourses influence both

meaning-making of disability and the impact that this meaning-making has on identity

construction.

The relationship between identity construction and stories are influenced by both

cultural and relational discourses. Where an individual may call upon a greater cultural

narrative of disability when making sense of how they see themselves, relational

narratives impact meaning as individual experiences of their communicative partner can

impact how the disabled person is perceived. Through the use of stories, both cultural and

relational influences and impacts the discourses at play and can shed light into how each

communicative partner experiences disability.

Communication scholars have positioned the importance of stories as a mechanism of discursively negotiating identity. In family communication, stories and narratives discursively define the boundaries of family (Koenig-Kellas and Trees, 2008), non-normative family structures are discursively negotiated through stories (Koenig-Kellas, Baxter, LeClair-Underberg et al, 2014) and the role of stories and storytelling can communicate familial identity throughout generations (Ballard & Ballard, 2014). In interpersonal communication, scholars have not utilized stories with the same depth and this study provides a necessary step in expanding the use of stories and narratives in understanding non-familial, disabled identity.

Stories provide a unique methodological tool in that participants' who share their stories are engaging in decision making on what stories to tell, how to tell them and what details to include. This draws upon the power of everyday talk and allows researchers an insight into how individuals communicatively negotiate their identities. Further, the use of stories also shed light into how boundaries, privacy and disclosure are all being used when describing the self. Interestingly, if paired with a discourse-based theoretical methodology, additional insight can be gleaned from language choice, detailed understandings of cultural scripts and contextualizing relational history and assumptions within the context of storytelling.

This area of significance for this project was fleshing out the discourses that have theoretically framed by disability scholars and connecting discourses that have often remained separate. By collecting the stories of persons with newly acquired physical disabilities, we are able to see both the impact of cultural narratives on individual

experience and the role of individual experience on making sense of disability. This

becomes an interesting exercise for interpersonal communication as disability scholars

have not looked at the impact of disability on identity within a relational context.

Furthermore, until this project, disability scholars have not explored the impact of

disability on meaning-making from a critical discourse perspective. Critical interpersonal

scholars who are concerned with the use of language now have new insight into the

relationship between a dominant monologue and reconstructive discourses.

Practical Application

The practical application of this project provides meaningful understanding of

how people understand and feel about having an acquired physical disability. More

accurately, application of this research can be used in personal, professional and

academic environments. According to the CDC (2014), more than one in three women

and one in two men are projected to experience disability within their lifetime and the

need for disability-related research becomes high. Currently, significant amounts of

empirical research exist surround physical disabilities. For example, in the United States,

there are approximately 270,000 individuals with a spinal cord injury (SCI) with 12,000

new persons added each year (NSCISC, 2012). Additionally, between 1.7 million and 2.3

million people are treated each year for a traumatic brain injury (TBI) and of this number,

approximately 70% (1.2 to 1.6 million) survive and are left with permanent disability

(CDC, 2014). In the United States, approximately 800,000 Americans have a stroke

annually, while 16% or 130,000 of individuals die from stroke or complications

surrounding the ailment (Stroke Association, 2016). Strokes are currently the leading

cause of permanent disability within the United States. These are just three types of acquired disability. There are literally hundreds more. Currently in the United States, more than 35.6 million Americans have some form of severe physical disability that requires assistive technology. This does not include eye glasses (Brault, 2012).

With all of these statistics in mind, the amount of research looking at the experience of having a disability is limited. In my own narrative shared at the beginning of this project, I note that my own rehabilitation was conducted with 25-year-old materials and VHS tapes from the early 90s/late 80s. Translating this project into relative materials can be very informing for rehabilitation professionals. Specifically, when focused on the marginalized disability discourse of normalcy. As mentioned in the review of literature, current rehabilitation literature focuses on autonomy and self-care, yet does not address the meaning of having an acquired physical disability in the context of relational, work-based and academic spaces.

In relational contexts, this research provides insight into the family, friends and individuals who interact with a person who has an acquired physical disability. Moreso, this provides them the ability to not only look at how they think about having a disability, but see how their messages reflect their feelings relating to meaning-making and disability. The more a person can understand how their messages are being interpreted, the more likely they are to construct messages that communicate effectively what they are trying to say. There were multiple examples in this project where persons shared that they knew the people talking to them were not intending to be offensive (i.e. praying for a cure), yet the act itself challenged their personal legitimacy. Another example out of this

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project comes in the critique of the Autism Speaks organization. They are committed to finding a cure for autism and those who belong to the community of persons with autism are upset, as they do not feel it appropriate to have to "cure" their life (Parsloe & Holton, 2017).

Rehabilitation specialists can also use the descriptions of the discourses and the testimony and exemplars from the participants to reanalyze their own speech and ways of talking of disability. By being able to see how the experience is for persons outside of rehabilitative spaces communicate about having a disability, new curriculum and trainings can be done to normalize having a disability. In the example where the young woman was called out by her father for wanting to be a physical therapist, there was no affirmation from the therapist that this would even be possible. Whether this is the case or not, knowing the impact of such messages can positively or negatively impact a person's ability to construct a positive meaning to having a disability.

Additionally, information from this project can be translated into how different organizations communicate about disability. Institutions such as Craig Hospital in Denver, Colorado or the Miami Spine Project can craft communication that supports normalcy alongside autonomy without positioning persons with disabilities in a negative position. Current messages from these organizations and organizations like them, utilize war or aggression metaphors in communicating about disability. Research surrounding people who have been diagnosed with cancer or who have had strokes also challenge these metaphors as these conditions are not chosen, but brought on by a variety of factors (Cap, 2017). In all of these cases, the language used in talking about a particular type of

disability influences how persons communicate and make sense of the different types of disability.

Outside of research, the information from this project can be utilized by academic professionals who work directly with students, staff and faculty with disabilities. Currently, many higher education institutions are struggling to serve the community of persons with disabilities inside their own institution. Resources are low and education is in high demand. From web accessibility to physical accommodations, higher education as a whole exists within a reactive system. More accurately, in many higher education based spaces, institutions will accommodate when requested, but will not work to create a proactive space for persons with disabilities (AHEAD, 2016). This shortcoming is almost always due to budgetary or physical limitations of the staff. Messages surrounding accessibility and disability in higher education is worded from a reactionary perspective and often works against their inclusive learning environment mission.

From our own institution, we have the following statement, DSP is dedicated to giving students with disabilities an equal opportunity to participate in the University's programs, courses and activities. DSP provides accommodations at no cost to any student who has a documented disability as required by the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. Accommodations afford students equal opportunity to participate in the University's programs, courses, and activities.

In this statement, we see that DSP provides accommodations at no cost to any student with a documented disability. The latest reports show that between 12-15% of students in higher education have a disability, yet less than 5% of them are documented.

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Utilizing our understanding of how the different discourses work can create positive change for persons with any disability in higher education.

Specifically, by understanding how the biomedical discourse of disability works, institutions can begin to shape their language surrounding disability from being positioned negatively against ability, or moving away from language that paints having a disability as lesser; To utilizing language surrounding disability into a more normalizing and inclusive space. This in turn could help higher education institutions in meeting their mission statement for inclusive spaces and help serve the 7 to 10 percent of students who remain undocumented.

Limitations

The limitations of this project were apparent in the diverse narratives shared by the participants. Unlike other characteristics that are ascribed to individuals, disability affects persons very differently (Shapiro, 1994). As I was worked through the narratives I noticed major differences in how each individual frame having a disability. More accurately, having a disability was often l couched between the impact of the disability on performing everyday tasks and how having a disability impacted interpersonal relationships. To plainly speak, throughout the interviews, it seemed that the more limited a person was in their ability to live autonomously, the more likely they were to reflect upon their disability or the experience of having a disability negatively.

A challenge arose in the breadth of the definition of an acquired physical disability. A person who loses their sight has what seems to be a very different disability experience than someone diagnosed with a chronic auto-immune disorder or a person

who suffers a traumatic brain injury. Additionally, the method of acquisition seemed to also impact how persons framed the experience of having a disability. This became apparent with the participants who were blind and those that had a traumatic brain injury. The commonalities that did arise were discussed earlier, but the analysis was extraordinarily difficult.

Using a critical discourse lens, specifically one that was influenced by relational dialectics made analyzing and understanding meaning making and disability very difficult. Each person framed their disability by speaking of what they could not do, or how having a disability negatively impacted them. Even in the spaces where they spoke of their future hopes, dreams and projects, participants shared a narrative of hope and change. Using an adapted form of McAdam's original life story interview protocol from 1993, this project would have benefited from his redemptive turn in the early 2000s. To more accurately speak, the types of stories that emerged in this project were illustrations of how the participants made sense of acquiring a disability. There hopes and dreams reflected their desires for change to be created by them and for others. In 2000, McAdams presents a semi-biographical example that illustrates how American identity lies within the stories we share. When bad things happen, and they do to everyone – we use these narratives to speak to how we overcome and garnish admiration from others. My participants were doing just this, and they found that when they spoke to someone who had a very similar, yet very different story, they framed their stories to match what they perceived my story to be.

This becomes significant as my insider status affected the depth of detail participants shared in their stories. Where people would say things like, "You know how it is" or "you know what I mean?" it displays a level of shared experience and insight, which I recognize as the primary researcher to be important to note. Adler and Adler (1987) label this as their third membership role, complete membership researcher.

Another limitation in this study was allowing the participant to define when they acquired their disability. An example shared earlier, a woman was diagnosed with late-onset juvenile rheumatoid arthritis. She learned of her diagnosis when she took a step and her thigh bone punctured through her hip bone. In her reflection, she explained that this diagnosis was able to make sense of illness that she experienced earlier in her life. So even though she identified for this project as having acquired a disability within the previous three years – she has lived with it for her entire life and is able to retroactively apply an explanation or make sense of the uncertainty that did or does exist within her lived experiences. This was also the case for a person with cystic fibrosis, he identified as having newly acquired the disease when it started to actually impact his independence. He has lived with the diagnosis for almost 7 years, but did not have any real symptoms until 2013. Other participants identified their acquisition of a disability, but didn't start counting time until they awoke or until they had competed rehabilitation. For the same justification that I made when I proposed this study with allowing the participant to define when they acquired their disability, I do have to list it as a limitation. Moreover, this study was bound to limited context. The participants varied personal and family histories, political affiliations, ideals, the context of the study, familial support, presence

of a significant other, number of friends and the qualities of all of those relationships impact their sense-making and story choices.

An additional limitation tied to insider status is in the choices in stories that participants chose to share. As a person with an acquired physical disability, doctoral candidate and father of four, my story is considered a success. In a candid conversation with one of my participants, she shared how excited she was in how well I was doing since high school. She had heard of my accident in college and was always so sad about what happened. When we connected in the mid-2000s via Facebook, she found herself happy that I was still in school and married. For every interview, I painted a picture of my life. After every interview, I spoke candidly with the participants. For those who recommended people, I have no way of knowing how I was described or what information was shared about me. However, the fact that I am also a person with a physical disability that is studying stories related to acquiring a physical disability, the stories that participants chose may have been crafted to keep face with me or their perception of me. The limitations of the study were all learning experiences that either supported what I should have known or provided a justification for future research.

Future Research

A number of potential future studies can be done from this work. First, a longitudinal study could be conducted on the individuals who participated in this study. It would be interesting to see how the stories they shared would change or be replaced by new lived experiences. Throughout their lives, new experiences would shape their story

choices, the details they shared and the language they choose. This would provide an interesting space to compare and contrast the experiences of having a disability over time.

Second, further research could be conducted on persons with similar acquired disabilities. As there was not an acquired disability category or diagnosis with more than four persons (Blindness and Traumatic Brian Injury), finding more persons with similar experiences would help deepen our understanding of their experiences and how they talk about having a disability. An additional turn to this line of research would be to find persons who either have congenital disabilities and contrast them to persons who acquire similar disabilities.

Third, recoding all of this data with McAdams (2000) turn towards redemptive cycles would provide a different level of data. This analysis would allow us to study the second half of the data and contrast it against what has already been done. It would also provide further insight into how other identities are constructed communicatively in tangent with the disabled identity by exploring how persons reframe experiences in a manner that frames how they tell stories.

McAdams argues that our identities are constituted within our stories and by coding for redemption, we can begin to explore how persons with disabilities perceive themselves within a greater cultural narrative of ability. Although not exhaustive, a future direction of research would be to complete a full contrapuntal analysis to explore the interplay of the biomedical discourse of disability and disability discourse of normalcy. This would provide further insight into the relationship between privileged discourses and marginalized discourses, specifically when the centered discourse is an

overwhelming monologue. Further this approach would also lend additional

understanding of post-modern critical theory as the discourses at play are far from equal

in value or construction (Baxter & Asbury, 2014).

CHAPTER SIX: CONCLUSION

At the beginning of this project, I told the story of how I became disabled. I included details about the accident itself, the first few days and the following months of rehabilitation. I transitioned into my return to college and the beginnings of my academic career. I would like to revisit the moment in my mentor's office that I mentioned at the end of my narrative.

I owe a lot to Dr. Scott Dickmeyer. On that day, as I walked into his office, I did not realize that this was the start of my actual academic journey. Up until that point, earning a degree was a means to an end, an avenue for a job or possibly the justification for entrepreneurship. He knew in that space that I had very little understanding of academic research and yet he listened to me rant and critique the articles that he assigned. At the end of that conversation, after stringing a series of "what about . . ." questions together, he smiled and told me that I could be the one to answer them. That I could take steps in my future to address or redress the questions that emerged from the readings. His encouragement, paired with the support of my friends and family have led me through an incredible journey.

As I graduated with my bachelor's in Communication Studies, I knew that this was the path that I wanted to be on. I thought, by the time I completed my doctorate, I would have the answers that I was seeking. I wanted to understand how people made

sense of their disability, their relationships and their lives. This journey for answers has taken me 13 years. During this time, I have spent well over one hundred thousand dollars. I have traveled to 19 states and have met with more than one hundred people with a variety of disabilities. I have written thousands of pages and have read hundreds of thousands of pages. And in the end, as I sit reflecting upon my journey, I realize that I still do not have the answers that started me on this quest.

This should bother me, but it does not. In fact, the unknowing drives me to move forward. The path that I have taken has provided me a positive outlook to life, given me a great family, a fulfilling career and the ability and skills to understand the world in a more critical and engaging way. As a student, I was introduced to the world of Communication Studies and in turn my scholarship, my teaching and my personal life has become better for it.

Reflecting on the Project

This project will serve as a foundation to my work as my move forward in my career. I learned a lot about who I am as an academic, a teacher, an advocate and a person with an acquired physical disability. This project was more difficult than anything that I could have imagined. I was forced to face my on demons surrounding disability and I realized that although I believed I had coped with acquiring my disability, this experience displayed what Trehane (1990) posited as the process of coping. Listening to each person tell their stories of success and failure, struggles and challenges and love and hope has provided a unique space to reflect on why I chose to do this topic.

My choice in studying persons with newly acquired physical disabilities has been following me around for years. When I acquired my disability in 2002, there was no manual or mentorship available for me to learn what it meant to be a person with a disability. Up until that point, I really did not know anyone with any sort of visible physical disability. I grew up in a reasonably affluent, White and Christian community. Our schools segregated persons with visible disabilities and I really had no measure on how to act or interact with others. As I negotiated my new identity, I had to build and rebuild friendships, expand my own worldview and learn how to find where I fit within the greater narrative of our world. I found myself asking questions to anyone who would listen and I had to carve out the space that I now occupy through a lot of heartache, frustration and uncertainty.

My choice in theoretical lens was suggested to me by my advisor. Working on a project with my advisor prior to the start of my dissertation, I was introduced to Baxter's (2011) Relational Dialectics 2.0 (RDT 2.0). This theory is challenging and has forced me to look beyond performed phenomenon into the ways that we use language. Methodologically, Leslie Baxter, the creator of RDT 2.0 suggested that I look at McAdam's Life Story Protocol as a tool for data collection. I have always been fascinated by the works of Bochner and Ellis, Koenig-Kellas and Trees, Ballard and Ballard and other scholars who explore storytelling was a methodological tool, I was immediately intrigued. Not just in the stories, but in "how" behind the ways that individuals tell stories. Adapting McAdams (1993) Life Story interview protocol was my

advisor's idea and doing so led me to collect an incredibly rich and interesting body of data.

There were two very difficult areas to this project. Finding participants who were willing to share their stories. What started out as a series of advertisements turned into a very large and complex process of snowball sampling. At times, I thought I would never find enough people to interview an thanks goes out to all my participants who tapped their communities, their circle of friends and colleagues and their networks for support. What I had hoped would take a month or so to collect, took more than half a year.

The other difficult aspect of this project came in collecting the stories. In normal conversation, stories beget stories. By prompting my participants, they would share their (sometimes highly) intimate stories with me and I was unable to share my own experiences with them. Every interview spanned a gamut of emotions and would often transition from crying to laughing to more crying. Emotionally, this was difficult for me to go through. Over the course of the three years that this project took to complete, I was ready to walk away at least a dozen times. Listening to individuals who have also experienced the acquisition of a disability speak about their challenges and heartaches is awful. Their stories stirred up my own insecurities and negative feelings that have been buried under years of academic work. The emotional labor took a toll and I know that a short break is necessary for me to process this experience.

Positionality

My positionality throughout this project has carried insider status. As a person with an acquired physical disability, I find that I am constantly connecting the

experiences of my participants to areas of my own life. As I analyzed this data, I struggled with my own bias as I often understood their viewpoint and ensuring a level of objectivity was difficult. Throughout the interviews, people who use phrases like, "You know what I mean," which was there way of implicating my disability as a currency for validity. Most of the time I would recognize this and ask them to continue to explain, but I wonder if they would have shared what they did, if I had appeared or if they would have known I was able-bodied.

Additionally, in having a disability myself, I was able to look at stories through a different lens. Many of the experiences shared throughout these experiences connected in some way to experiences that I have had over the past 15 years of having a disability. Being able to relate to those experiences first hand provides a level of understanding that cannot be imitated. For example, when my participant Lori shared her experience of being blind and not seeing, I could reflect and connect to that as I try and articulate what it is like to not feel my own legs or being able to use them. This positionality informs my opinions and my reflections on this project.

I also recognize that as a researcher with a visible physical disability, who studies persons with physical disabilities, my body provides a contextual space that influences my participants. During the interviews, many participants reported that they felt comfortable sharing their with someone who knew what they were going through and many commented that they liked being able to talk about their lives with someone else like them. Interestingly, I believe my position as a member of the old guard, or as one of my participants articulated, "I had been around the block and knew what was up" helped

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tease out details that might not have come for other researchers. Overall, my membership in the disabled community benefited this project.

Opinion on Results

The essence of this project was steeped in Baxter's (2011) Relational Dialectics theory and Contrapuntal Analysis. I completed the thematic discourse analysis but did not move past a surface level examination of the talk. Rather, I identified the discourses that I saw present within the stories and explored their construction and briefly – their relationship to each other. I believe this project to be positioned strongly in what Baxter and Bakhtin label as the distal-already spoken, as the greater cultural narratives were represented in the participant's experiences.

I do not believe that the biomedical discourse of disability is in opposition to the disability discourse of normalcy. As I argued throughout this project, I believe that both discourses are juxtaposed. They are not transformed or broken apart, nor do they exists in a direct centripetal/centrifugal relationship with each other. Further support for this juxtaposition is in the deconstruction of ability and disability and their existence on a spectrum. To illustrate this point, let's unpack a common example of disability and how it is constructed to not be considered a disability.

According to the Vision Council of America (2011), 75 percent of adults use some form of vision correction with more than 60 percent of this number using glasses, while the remainder wear contact lenses. With such a high percentage of persons needing corrective lenses, the way we talk about this deficiency has been normalized. When people talk about their vision, they will say, "I am blind without my glasses." Very rarely

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do they actually mean what they say. In our world, we have people who struggle with their vision and cannot use corrective lenses (assistive technology) to see, and some identify as persons with low vision, while others identify as blind.

This identification of a disability has normalized within our culture. With such a high percentage of persons using corrective lenses, and the need for this technology being an often gradual change over time – we do not recognize the need for corrective lenses as having a disability. In comparison, less than 25 percent of children under the age of 10 wear glasses, and 30 percent of children between the ages of 14 and 17 wear corrective lenses (VM, 2012). From age 10 through age 17, the percentage of children wearing glasses or contacts increases by 5 percent. Additionally, this growth exponentially grows throughout adulthood and like many disabilities, become acquired through age. I would argue that this gradual change correlates to how our language has normalized this disability.

When people say, "I am blind without my glasses" they are invoking the biopolitical discourse of disability as they are using non-abled language to normalize their disability; While individuals who say, "I cannot see very well without my glasses" are employing the sociolinguistic discourse of disability. In both cases, they are normalizing a disability through their speech. When structured within the framework of discourses, I would argue that a contrapuntal analysis could be conducted within the disability discourse of normalcy as the use of language in that space moves between abled and non-abled/literal language.

Next Steps

I do plan to revisit this data at a future point. As mentioned above, I believe that a contrapuntal analysis could be done using the disability discourse of normalcy and I would like to explore this in the future. Additionally, I would like to look more at how individuals perceived their futures as every single person interviewed in this project, talked in depth about how their life project centered around informing others on what their lives were like. I would like to recode this data with McAdams (2000) redemption cycle in mind. He posits that we tell stories of hardships in ways that provide a positive outcome. He argues that this is a uniquely American phenomenon that informs our identity construction. I would like to explore how redemption and uncertainty interact. When it comes to our society, uncertainty plagues what we know about having a disability and each person that I talked with spoke to their desires to inform others. This is why I do what I do. I study this community of persons, using the tools that I do, to help give a voice and dispel the myths and uncertainties that surround my own life. Where some of my participants are choosing to write books, or act as inspirational speakers; I research, I write and I teach.

I do not know what my future holds, nor do I know how long I will stay within the academy. This past year I have worked as support staff at a local community college. The work is tangentially tied to persons with disabilities and my time outside of a classroom has stirred up feelings of longing to be back in a classroom. I enjoy teaching and my research informs my positionality as such.

As I conclude this project, I cannot help but look at the impression that this research has left on me. For the past three years, I have struggled with my own demons of being a disabled disability researcher doing research on disabilities. As I set down my pen, I am thankful for the experience and forever changed by the stories I have heard. I am a little bruised and slightly battered, but as I heal – I will continue this work.

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APPENDIX A: THE DISABILITY LIFE STORY INTERVIEW

Originally created by Dan P. McAdams, 1985

Revised and Adapted in 2014 by Brian Grewe Jr., University of Denver Interviewer Copy

Introduction

I want to begin by thanking you for agreeing to do this interview today. It is important for us to learn how ideas of ability permeate our everyday lives and your story will help us do just that. As I am the primary interviewer, I will be asking you a lot of very personal questions. Therefore, I believe it to be important to share with you my own story.

Like any tale, there is a beginning, a middle and an end. For me, I was born and raised in White Bear Lake, Minnesota, I was a musician, an athlete and a geek. My real story begins after my first year of college, the summer of 2002, I was a door-to-door salesman for a Tennessee-based education company. The company placed us outside of Houston, Texas and for that summer, I worked 90 hour weeks with about 40 other native mid-westerners. At the end of the summer, I decided to finish a week early so I could head back to college for our Marching Band's "Hell Week." I was not the only one heading home early and a group of four of us ended up carpooling back to Tennessee before making the trek to college.

On August 20th, 2002, at 4:36 a.m., the car I was travelling in was involved in a single-car accident. The driver had fallen asleep and I was already asleep in the backseat. We crashed into a ravine, striking a tree at over 70 mph. I was ejected from the vehicle and when I awoke, I was already inside of the second hospital. After four different

hospitals, I was diagnosed with having a severe spinal cord injury. For all intents and purposes, I have an incomplete T8, complete T10 spinal cord injury and have paraplegia. I spent three months in an in-patient rehabilitation facility and 8 weeks in an outpatient. After this, I immediately returned to college, and have tried to live an independent life as possible.

I wanted to tell you my story so that you can see that I have also experienced what it is like to acquire a disability. Now, although I cannot truly know what it is that you have gone through, I can and will be able to empathize. I would like you to feel free in sharing your stories, however, if at any point you feel uncomfortable or wish to conclude this interview, you may do so by simply asking. You will be recorded via a digital audio recorder and this interview may be transcribed. As we finish each section, I will let you know that we will be moving on. Throughout this interview, I may take notes on the stories you are sharing, and I may note the time stamp for later reference. I hope that you will enjoy the interview process. Do you have any questions?

Introduction to Participant

This is an interview about the story of your disability. As a social scientist, I am interested in hearing your story, including parts of the past as you remember them and the future as you imagine it. The story is selective; it does not include everything that has ever happened to you. Instead, I will ask you to focus on a few key things in your life – a few key scenes, characters, and ideas. There are no right or wrong answers to my questions. Instead, your task is simply to tell me about some of the most important things

that have happened in your life regarding your disability and how you imagine your life developing in the future because of it.

Part One: Life Chapters.

Please begin by thinking about your disability story as if it were a book or novel. Imagine that the book has a table of contents containing the titles of the main chapters in the story. To begin here, please describe very briefly what the main chapters in the book might be. Please give each chapter a title, tell me just a little bit about what each chapter is about, and say a word or two about how we get from one chapter to the next. As a storyteller here, what you want to do is to give me an overall plot summary of your story, going chapter by chapter. You may have as many or as few as you would like.

Part Two: Key Scenes in the Life Story

Now that you have described the overall plot outline for your life with a disability, I would like you to focus in on a few key scenes that stand out within the story. I will be prompting you with a total of eight scenes within this section. A key scene would be an event or specific incident that took place at a particular point in time. Consider a key scene to be a moment in your life story that stands out for a particular reason – perhaps because it was especially good or bad, particularly vivid, important, or memorable. For each of the eight key events, I ask that you describe in detail what happened, when and where it happened, who was involved, and what you were thinking and feeling in the event. In addition, I ask that you tell me why you think this particular scene is important or significant in your life. What does the scene say about you as a person? How does that experience affect who you are today? Please be specific.

Scene One: The High Point

Please describe a scene, episode, or moment in your life that relates to your disability story that stands out as an especially positive experience. This might be the high point scene of your entire life, or else an especially happy, joyous, exciting, or wonderful moment in the story. Please describe this high point scene in detail. What happened, when and where, who was involved, and what were you thinking and feeling? Also, please say a word or two about why you think this particular moment was so good and what the scene may say about who you are as a person.

Scene Two: The Low Point

The second scene is the opposite of the first. Thinking back over your life of having a disability, please identify a scene that stands out as a low point, if not the low point in your life story. Even though this event is unpleasant, I would appreciate your providing as much detail as you can about it. What happened in the event, where and when, who was involved, and what were you thinking and feeling? Also, please say a word or two about why you think this particular moment was so bad and what the scene may say about you or your life.

[Interviewer note: If the participants balks at doing this, tell him or her that the event does not really have to be the lowest point in the story but merely a very bad experience of some kind.

Scene Three: Turning Point

In looking back over your life with a disability, it may be possible to identify certain key moments that stand out as turning points -- episodes that marked an important

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change in you or your life story. Please identify a particular episode in your life story that you now see as a turning point in your life. If you cannot identify a key turning point that stands out clearly, please describe some event in your life wherein you went through an important change of some kind. Again, for this event please describe what happened, where and when, who was involved, and what you were thinking and feeling. Also, please say a word or two about what you think this event says about you as a person or about your life. For all intents and purposes, you may use the moment of how you acquired or were diagnosed with your disability, but as it can be a longer story, please choose a specific moment within the larger story.

Scene Four: Positive Childhood Memory Relating to Ability

The fourth scene is an early memory – from childhood or your teen-aged years – that relates to (dis)ability and stands out as especially *positive* in some way. This would be a very positive, happy memory from your early years. Please describe this good memory in detail. What happened, where and when, who was involved, and what were you thinking and feeling? Also, what does this memory say about you or about your life?

Scene Five: Negative Childhood Memory Relating to Ability

The fifth scene is an early memory from childhood or teen-aged years that relates to (dis)ability and stands out as especially *negative* in some way. This would be a very negative, unhappy memory, perhaps entailing sadness, fear, or some other very negative emotional experience. Please describe this bad memory in detail. What happened, where and when, who was involved, and what were you thinking and feeling? Also, what does this memory say about you or your life?

Scene Six: Vivid Disability-Related Memory

Moving ahead into your adult years, please identify one scene that you have not already described in this section that relates to having a disability and stands out as especially vivid or meaningful. This would be an especially memorable, vivid, or important scene, positive or negative, from your adult years. Please describe this scene in detail, tell me what happened, when and where, who was involved, and what you were thinking and feeling. Also, what does this memory say about you or your life?

Scene Seven: Wisdom Event

Please describe an event in your disability story in which you displayed wisdom. The episode might be one in which you acted or interacted in an especially wise way or provided wise counsel or advice, made a wise decision, or otherwise behaved in a particularly wise manner. What happened, where and when, who was involved, and what were you thinking and feeling? Also, what does this memory say about you and your life?

Scene Eight: Religious, Spiritual, or Mystical Experience

I honestly recognize that not everyone believes in a religious, spiritual or mystical doctrine. However, I do believe that we all have moments in which we experience something that cannot be explained rationally. Thinking back on your life with a disability, please identify an episode or moment in which you felt something like this. This might be an experience that occurred within the context of your own religious tradition, if you have one, or it may be a spiritual or mystical experience of any kind. Please describe this transcendent experience in detail. What happened, where and when,

who was involved, and what were you thinking and feeling? Also, what does this memory say about you or your life?

Part Three: Future Script

The Next Chapter

Your life story includes key chapters and scenes from your past, as you have described them, and it also includes how you see or imagine your future. Please describe what you see to be the next chapter in your life. What is going to come next in your life story? Who is present? Where will this chapter take place? What role does your disability play?

Dreams, Hopes, and Plans for the Future

Please describe your plans, dreams, or hopes for the future. What do you hope to accomplish in the future? Please describe what you want to accomplish, experience or achieve. Has the recent acquisition of your disability, affected these goals?

Life Project

Do you have a project in life? A life project is something that you have been working on and plan to work on in the future chapters of your life story. Acquiring a disability might have impacted the project, and if it has, speak to how you see yourself adapting to still accomplish this goal. The project might involve your family or your work life, or it might be a hobby, avocation, or pastime. Please describe any project that you are currently working on or plan to work on in the future. Tell me what the project is, how you got involved in the project or will get involved in the project, how the project

might develop, and why you think this project is important for you and/or for other people.

Part Four: Challenges

This next section considers the various challenges, struggles, and problems you have encountered in your life. I will begin with a general challenge, and then I will focus in on three particular areas or issues where many people experience challenges, problems, or crises. In front of you is a brief description of each prompt. You may, if you choose to, speak about your disability in any or all of these areas, but I ask that each story be uniquely different.

Life Challenge

Looking back over your entire life, please identify and describe what you now consider to be the greatest single challenge you have faced in your life. What is or was the challenge or problem? How did the challenge or problem develop? How did you address or deal with this challenge or problem? What is the significance of this challenge or problem in your own life story?

Health

Looking back over your entire life, please identify and describe a scene or period in your life, including the present time, wherein you or a close family member confronted a major *health* problem, challenge, or crisis. Please describe in detail what the health problem is or was and how it developed. If relevant, please discuss any experience you had with the health-care system regarding this crisis or problem. In addition, please talk

about how you coped with the problem and what impact this health crisis, problem, or challenge has had on you and your overall life story.

Loss

As people get older, they invariably suffer losses of one kind or another. By loss I am referring here to the loss of important people in your life, perhaps through death or separation. These are *interpersonal* losses – the loss of a person. Looking back over your entire life, please identify and describe the greatest interpersonal loss you have experienced. This could be a loss you experienced at any time in your life, going back to childhood and up to the present day. Please describe this loss and the process of the loss. How have you coped with the loss? What effect has this loss had on you and your life story?

Failure, Regret

Everybody experiences failure and regrets in life, even for the happiest and luckiest lives. Looking back over your entire life, please identify and describe the greatest failure or regret you have experienced. The failure or regret can occur in any area of your life – work, family, friendships, or any other area. Please describe the failure or regret and the way in which the failure or regret came to be. How have you coped with this failure or regret? What effect has this failure or regret had on you and your life story? How does this relate your disability?

Part Five: Personal Ideology

Now, I would like to ask a few questions about your fundamental beliefs and values and about questions of meaning and morality in your life and how that relates to having a

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disability. Please give some thoughts to each of these questions. You may speak freely, but please illustrate these thoughts through an act, scene or episode of your life.

Religious/Ethical Values

Consider for a moment the religious or spiritual aspects of your life. Please describe in a nutshell your religious beliefs and values, if indeed these are important to you. Whether you are religious or not, please describe your overall ethical or moral approach to life with a disability

Political/Social Values

How do you approach political or social issues? Do you have a particular political point of view? Are there particular social issues or causes about which you feel strongly? Does your disability play any part in how you view these issues? Please explain.

Change, Development of Religious and Political Views

Please tell the story of how your religious, moral, and/or political views and values have developed over time. Have they changed in any important ways because of your disability? Please explain.

Single Value

What is the most important value in living with a disability? Please explain.

Other

What else can you tell me that would help me understand your most fundamental beliefs and values about life and the world? What else can you tell me that would help me understand your overall philosophy of living with a disability?

Part Six: Life Theme

Looking back over your entire life story with all its chapters, scenes, and challenges, and extending back into the past and ahead into the future, do you discern a central theme, message, or idea that runs throughout the story? What is the major theme in your life story and living with a physical disability? Please explain.

Part Seven: Reflection and Wrap-Up

Thank you for this interview. I have just one more question for you. Many of the stories you have told me are about experiences that stand out from the day-to-day. For example, we talked about a high point, a turning point, a scene about your health, etc. Given that most people don't share their life stories in this way on a regular basis, I'm wondering if you might reflect for one last moment about what this interview, here today, has been like for you. What were your thoughts and feelings during the interview? How do you think this interview has affected you? Do you have any other comments about the interview process or anything that you wish to add to help me better understand you?

APPENDIX B: SOCIAL MEDIA FLYER

Dear Facebook Friends,

I am asking for your help today. I am currently undergoing recruitment for a study on how people construct identity after acquiring a physical disability. I am currently recruiting adults over the age of 18 with physical disabilities that they have acquired within the past three years. If you do not qualify, but may have someone within your network of friends, would you be willing to post this as your Facebook status update?

Study Announcement:

If you are over the age of 18 and identify with having acquired a physical disability within the past three years, please consider participating in a study that is being conducted by Brian Grewe Jr., (MA, 2010), a doctoral candidate, at the University of Denver under the supervision of Dr. Elizabeth A. Suter (PhD, University of Illinois at Urbana-Champaign), Associate Professor of Communication Studies, University of Denver.

Hello, my name is Brian Grewe and I am conducting a study to complete my dissertation on the identity constructions of persons with newly acquired physical disabilities. I am currently seeking individuals over the age of 18 who have acquired a physical disability within the past three years. Participating in this study would require you to engage in a 90 minute interview chronicling your life story and completing two short worksheets. The interview will take place at a time and location that best suits your needs. As I am located in Denver, Colorado, I am also a person with a physical disability and this limits how far

and where I can travel to. However, a mutual location can be arranged. Please note that all information will be kept confidential and participation is completely voluntary.

If you are interested in participating, please contact me at bgrewe@du.edu or by telephone at 612-414-6723. If you do not qualify, please consider sharing this announcement via Facebook status sharing or through e-mail with anyone that you feel may be interested in.

Warm Regards,

Brian

APPENDIX C: EXPLANATION SCRIPT

Invitation to participate in a research study

The purpose of this study is to understand the process of identity construction for persons with newly acquired physical disabilities. The study uses a life story interview to collect information about your lived experiences. The stories you share will then be analyzed for language, content and overall context. You have been asked to participate as you have identified that you have acquired a physical disability in the past three years. You are being asked to be in this research study because you have identified as an adult over the age of 18 who has acquired a physical disability within the last three years.

Description of subject involvement

If you agree to be part of the research study, you will be asked to participate in a life story interview that will take place at a time of your convenience. This interview will take about 90 minute to complete.

Possible risks and discomforts

The researchers have taken steps to minimize the risks of this study. Even so, you may still experience some risks related to your participation, even when the researchers are careful to avoid them. These risks may include the following emotional distress resulting in the sharing of difficult memories or stories.

Possible benefits of the study

This study is designed for the researcher to learn more about how persons with newly acquired physical disabilities create and manage their identities.

If you agree to take part in this study, there will be no direct benefit to you. However, information gathered in this study may provide insight into how we understand identity construction in persons with physical disabilities. This also may result in a change of how medical professionals instruct and assist in the rehabilitation processes that many persons with newly acquired physical disabilities take part in.

Study compensation

You will not receive any payment for being in the study

Study cost

The interviews will occur at a time and location that is most convenient for you. Should you incur any costs of parking or transportation, please let the researcher know. Arrangements can be made to reimburse you for reasonable costs incurred for participating within this study. By agreeing to be in this study, you do not give up your right to seek compensation if you are harmed as a result of participation.

Confidentiality, Storage and future use of data

To keep your information safe, the researchers will take appropriate precautions in protecting your identity. This process includes removing any identifying information, including your name from any data. Instead, a study number and participant ID will be generated and attached to any transcribed data collected from this study. Your information will be kept on a password protected computer and all transcripts will have all identifying information removed including your name, and any other name listed within the stories.

The data will be stored in a locked file cabinet located within the researchers home and will be kept for up to 10 years. The *data* may possibly be made available to other researchers for other studies following the completion of this research study and will not contain information that could identify you. In the case another researcher views the data collected from this study, they will only have access with the involvement of the original researcher

The results from the research may be shared at a meeting. The results from the research may be in published articles. Your individual identity will be kept private when information is presented or published.

Who will see my research information?

Although we will do everything we can to keep your records a secret, confidentiality cannot be guaranteed. Both the records that identify you and the consent form signed by you may be looked at by others.

- Federal agencies that monitor human subject research

- Human Subject Research Committee

All of these people are required to keep your identity confidential. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

Also, if you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies.

Some things we cannot keep private. If you give us any information about child abuse or neglect we have to report that to Child Services and the local law enforcement agency.

Also, if we get a court order to turn over your study records, we will have to do that.

Voluntary Nature of the Study

Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. If you decide to withdraw early, the information or data you provided will be destroyed.

Contact Information

The researcher carrying out this study is **Brian Grewe Jr.** You may ask any questions you have now. If you have questions later, you may call **Brian** at **612-414-6723.** If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about; (1) questions, concerns or complaints regarding this study, (2) research participant rights, (3) research-related injuries, or (4) other human subjects issues, please contact Paul Olk, Chair, Institutional Review Board for the Protection of Human Subjects, at 303-871-4531, or you may contact the Office for Research Compliance by emailing du-irb@du.edu, calling 303-871-4050 or in writing (University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-2121).

APPENDIX D: E-MAIL CALL

Dear Friends,,

I am asking for your help today. I am currently undergoing recruitment for a study on how people construct identity after acquiring a physical disability. I am currently recruiting adults over the age of 18 with physical disabilities that they have acquired within the past three years. If you do not qualify, but may have someone within your network of friends, would you be willing to forward this along?

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telephone at 612-414-6723. If you do not qualify, please consider sharing this

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Warm Regards,

Brian