

I Am Not the Same Person, Even Though I Am:
Managing Communication and Identity in the Aftermath of Physical Disability

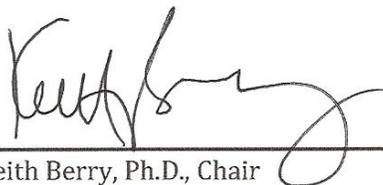
Luke Peter Green

University of Wisconsin-Superior

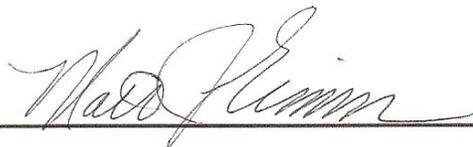
I Am Not the Same Person, Even Though I Am:
Managing Communication and Identity in the Aftermath of Physical Disability
Luke Peter Green
University of Wisconsin-Superior

This is to certify that the thesis prepared by Luke Green has been approved by his committee as satisfactory completion of the thesis requirement for the degree of Master of Arts.

Approved by:



Keith Berry, Ph.D., Chair



Martha J. Einerson, Ph.D., Committee Member



Ephraim Nikoi, Ph.D., Committee Member

Table of Contents

Abstract	4
Acknowledgments	5
Dedication.....	6
Chapter 1: Who I Was, Who I Am and How It was Communicated	7
No Longer the Same.....	7
Helpful Others	18
Rationale	24
Plan of Study	27
Chapter Two: Making Sense of the Change Disability Brings.....	29
Literature Review	29
Research Questions.....	36
Analysis.....	37
Data Collection	38
Ethical Considerations	41
Participants.....	44
Chapter 3: I’m the Exact Same Person I Was Prior, Except.....	46
Mike	46
Ryan	55
Sara.....	64
Greg.....	76
Chapter 4: I’ve Changed. I Don’t Mind.....	90
Going Forth.....	95
Limitations of the study	96
Areas for Future Research	99
No Longer the Same?.....	100
References.....	104
Appendix I	106
Appendix II.....	108
Appendix III	115

Abstract

The following explores changes that occur in communication following the acquisition of a physical disability. Framed by the symbolic interactionism theoretical tradition, I use ethnography and semi-structured interviews to further understanding of this dynamic communicative environment and its impact. I address the changes that occur after becoming disabled in terms of identity shaping communication, methods used to navigate the environment and mediate the changes, and the symbols that prevent clear communication from occurring. I argue that disability charges an individual to adapt their former identity and communication patterns in order to be successful in managing their new realities. My aim with this work is to bring awareness of the challenges those with acquired disabilities face in establishing and making sense of their new disabled identity.

Acknowledgments

I would like to acknowledge the team of individuals who have made this research possible. I would like to thank my thesis committee members: Dr. Keith Berry, Dr. Martha Einerson, and Dr. Ephraim Nikoi. In helping me revise and focus this project Dr. Berry, Chair, has gone above and beyond his duties. His devotion to motivating me to try my hardest and produce the best possible project is reflected in this document.

The participants who volunteered for this research are greatly appreciated. Their ability to recollect their personal experiences was instrumental and greatly shaped this entire project.

It should also be noted that Julie Ahasay and Dr. Tammy Ostrander are largely responsible for my desire to pursue communication as a field of study. The courses they led in my undergraduate studies ignited a fire within me.

I want to also acknowledge the entire UW-S Communicating Arts Faculty for fanning the fire I have for the discipline, one which remains engulfed in flames today. Our time has been brief but every moment has been rich in content.

Dedication

I dedicate this thesis to many people. First, I would like to thank my parents for all of the opportunities they have provided throughout my life. Without their love and support I simply would not be the person I am today. They have also provided me the preparation and means required to receive my most cherished possession, my education. Following my injury my Dad told me, "Keep your mind sharp. It is the one thing that cannot be taken from you. And you can do great things with it." I hope this work is the first of many great things to come from my education, a gift for which I am forever thankful.

I would like to thank my fiancée, Kristen. Her presence in my life has provided me with elation, inspiration and promise for the future in amounts that are immeasurable. We have been through an incredible amount in our years together and through it all she has remained a stalwart companion. The world is full of unpredictability. Whatever life brings us, good or bad; I readily await our next adventure we embark on together, side by side.

This dedication would not be complete without mention of the profound impact my family and friends have had in helping to positively shape my identity. I hope the experiences that we have shared together have been as beneficial and enjoyable for you as they have been for me.

Lastly, I dedicate this paper to those who strive to bring awareness to the impact of physical disability. Specifically, this is for those with and without disabilities who work hard to encourage and conduct research pertaining to the effects of disability socially and medically.

Chapter 1: Who I Was, Who I Am and How It was Communicated

No Longer the Same

In 2005 I identified as being a male, athletic, 17 year-old, senior in high school, and one who thrived in social situations. This identity was accompanied by many other typical attributes of a person my age. Traits that fit the themes relating to the ascension from adolescence to young adulthood: newfound independence, strength, invincibility, unabashed optimism, displayed testosterone, and sexual desire, to name a few.

I had a place within a collection of complex social circles. I demonstrated a laidback personality, which assisted in not being phased by the 'drama' of high school. I was admired for the athletic ability I displayed on the rink, court, and field. I was sought after for my optimistic attitude that never crossed a problem that could not be solved. Although these were just slices of my identity all three were central to who I was, and the identity I was selling.

Erving Goffman (1959) theorized that each person is a social actor carefully controlling how they represent themselves in the social world. My performance for the world was that I could handle any problem free from any aid, perform admirably in all things athletic, and I could expose humor and offer a positive spin in all situations. The first 17 years of my life I purposefully wove several distinctive moments together in order to establish and strengthen markers of my identity. I was sure to highlight my sporting successes and flaunt bad puns I had told as often as possible. I often found myself masking interests, such as my affinity for ceramics, in order to keep my projections consistent. Prior to any public performance every

personal fact, opinion, and story of mine had to pass my own gate keeping measures in order to achieve my identity goals. Taking these measures meant I was able to influence what people knew and thought about me. Through this practice I presented and established my identity.

On February 7, 2005 this managed presentation was put to the test after an unintentional collision during a hockey game left me and my brazen identity physically disabled. I suffered an incomplete spinal cord injury on my third cervical vertebrae. This diagnosis meant that all feeling and function below my neck was no longer in my control. Fortunately because it is an “incomplete” injury there still remained a chance for recovery and improved function.

Prior to the accident, ability had been closely related to many of the core identifying factors of who I was as a person. The moment the ability to move and feel sensations below my neck departed, so did my ability to ‘keep up the act’ of my now-former identity. The results forced a renegotiation of the entire spectrum of my social positions. Who am I as an individual if a large part of who I am no longer exists or is now false? In terms of my personal identity pre-injury I had gone from a somebody, to a nobody (or at best, a has been) in an instant.

Cognitively I was unharmed. I still retained my non-physical hobbies and interests, a majority of my passions, and grasped tightly to my optimism. I believed I was still “me,” albeit a stationary non-ambulatory me. To be sure, I felt I was the same person I was prior to my injury. This position would come to be tested when interacting with others.

During the first few weeks of my rehabilitation I noticed there were subtle differences in how others communicated with me, and caught myself shifting in how I addressed others. For example, during conversations anything I asked for was granted without question as if everyone had willingly become my suplicants and I was infallible. Overwhelmed by this power I became more passive as I was sick of playing boss to a group of yes-men. Initially I rationalized that changes were temporary, easily explained and justified by the situation. The cautious caring tones and word choice of others was simply a byproduct that accompanies any severe injury. I assumed, like similar unfortunate situations (e.g. a broken arm, severe illness), that, as the days passed people would realize all is well, moreover, all is the same, with me. They will come to see that intellectually I have not changed, and that regardless of the outcome of my recovery, I was going to remain the Luke they knew prior to February 7th.

It was important for me to maintain the entirety of my identity; it was all I knew. I enjoyed being known for the things, impressions for which I had tried so hard to manage. Insecurity and feelings of worthlessness accompanied the realization that I could no longer use sporting events to communicate my identity as a traditional athlete. I feared that, if I failed in keeping up this aspect of my performance, all of me would eventually be lost. I owed the respect and friendships I had garnered over the years to the acts I performed in the past. Physical ability was the cornerstone of many of my social connections. The relational services I was providing my friends via my physical abilities could no longer be delivered based on my acquired situation, this reality was crushing.

I remember the initial seven weeks after being admitted to the hospital was a psychologically trying time. Because I had been forced to comply with the routine of hospital life, any semblance of freedom or personal independence had been stripped away. Days were entirely structured beginning promptly at 6 a.m. and completed by an enforced 10 p.m. lights out. Leaving my hospital room in search of an environment that was less white, cold, and sterile was a three-step process which required the written approval of a nurse. All personal conversations could be, and most were, overheard by nursing staff or parents. The stark difference between my prior life as a high school senior, indeed, made my hospital stay feel Orwellian.

Perhaps this is because my well-being instantly became completely reliant on others. Thirst and hunger had to be satiated by nurses, family, or friends delivering nourishment right to my mouth. A voice activated call-button would alert a nurse to come into my room so I could let them know that my head had an itch in need of scratching. Showers which were once an extremely private thing now consisted of being strapped to a chair, to make sure I didn't fall out, while an attractive female nurse lathered me up and sprayed me down with a shower head. The toned athletic body that I was once so proud of now sat motionless, naked and exposed while being cleaned by an unfamiliar person in its entirety. This included my genitalia, which was now pierced by a catheter that assisted me in doing what is arguably the most personal thing a person can do. Although the staff at the hospital always operated with the highest level of professionalism, my self-worth pleaded no contest to the situations I perceived to be embarrassing and helpless.

There was no physical escape from those instances. I could only look inwards in attempt to distract my mind from the present. The resounding thought was always the same, "this is not normal." How had I reverted to this state? One that is so incredibly detached from the fledgling young adult I once was. Being under constant supervision and reliance had no part in my perception of normal.

My initial reaction of being bathed and dressed by another was that of shame. My idealized perception of a worthy individual included the ability to bathe and dress independently. My sense of identity felt as if it were decimated, because it didn't meet my own standards, which only served to intensify the feelings of vulnerability and helplessness brought about by my hygienic needs. Who was I as a person if I could not handle taking care of myself? Also, who was I as a man if I could not perform the physical roles that establish the traditional markers of masculinity? In my search for the answer I realized that I was asking the wrong question.

My physical ability is only one aspect inherent to the ways I perform myself, yet I let its absence conceal the rest of what and who I had to offer. My new routines were not normal in the eyes of my former self, but did the assistance in performing personal care justify throwing the entirety of my identity out? I incorrectly had been assuming that, because I was disabled and not normal, I was somehow less of a person, certainly less of a man. Over time, I embraced my new reality and realized a more salient question: what defines a person? Although the answer to this question is elusive, I believe we can agree that the answer is multifaceted and does not hinge on the success or failure of one litmus test (i.e. solely ability).

This personal readjustment I had in exploring this question was profound. Things that once made me who I was were not coming back, ever. Slowly I came to accept the reality that disability and all of its accompanying features would impact me forever. I now realized that I was no longer the person I once was, but that my new circumstances, regardless of how abnormal they were, could not prevent me from being just as admirable.

My newfound perspective allowed me to no longer be ashamed as a result of my limitations. I still had my cognitive abilities, positive personality traits, and wit, a fact I was ignoring during my initial recovery. In suffering my injury I experienced an episode which allowed me to reassess my definition of normal. The result gave me a unique perspective that reflected my experiences and new worldview. Catheters, wheelchairs, and requiring assistance were now parts of my reality, and soon became my new normal. In the eyes of a high school athlete the thought of having to live in a wheelchair is dreadful. However I was no longer the athlete I once was, so the new me embraced the wheelchair and the benefits it provided me. I understood there was nothing to be ashamed of, but would others?

In those trying weeks, I regained enough movement to operate a power wheelchair. The acquired independence, among other things, allowed me to venture beyond the constraining concrete walls of the hospital, my home away from home, for a few hours. I would join my longtime friends in a trip to see a movie and grab some dinner. Following weeks of uncertainty and chaos I was stable enough to exchange my therapy routine for that of a normal teenager. I had been anticipating the trip all week during my endless hours of physical rehabilitation. No

commitments, no obligations, no strangers invading my personal space. It was simply my girlfriend, Kristen, some friends and I, just like it was two months ago prior to me suffering my injury. It would be the first time since the injury that I would not be under the watchful eye of a nurse or chaperone figure. It was an opportunity for me to be a teenager again. I could just be me.

My friends and I gathered my support materials, meds, adapted silverware, and blankets to keep me warm. We then said goodbye to my mother, who naturally was concerned about my well being. We assured her and the nurses that we had everything required to make sure I returned unharmed. The scene was very similar to a parent sending their child off for their first sleepover. I remember the reassuring statements from my Mom. "You guys are going to have so much fun," she uttered in a way that feigned sincerity. I believe she wanted it to be true, but her concern for my wellbeing subverted her message. "Don't be getting into any mischief." Spoken again in a manner that probably intended one thing laced with joking sarcasm, but landed as "please don't let any mischief happen to you." Ten minutes after we left the parking lot my interpretation of my mother's messages was confirmed by the phone call we received making sure that everything is okay.

I was no longer her young child; I knew the risks of my departure and could likely evaluate any foreseeable mishaps. Although I needed as much support as a newborn physically, it was lost on many people that I was unharmed intellectually, as if the visual cues to a physical disability also report one's cognitive ability. It works like a presumption that, if I cannot take care of myself physically, my ability to reason and know what is in my best interests must also require the same level of

assistance, regardless of my ability to tell you differently. When these assumptions arose it prevented me from expressing my opinion or having a say in things as decisions were immediately and unjustly deferred to a caretaker viewed as “more competent.”

We continued on our way, and I knew it would be different with the elephant in the room that I was sitting on, my wheelchair, which visibly marked my disability. But as I had concluded, separate from my physical self and recent interpretations of the world around me, to anybody else's knowledge, I still felt the same. I came to figure that, injury aside, all other things remained constant (e.g. my friends were the same people, the activity was the same), so certainly my condition would not alter our fun night on the town (except, of course, for navigating the physical logistics of the environment). It didn't take long for me to learn that my logic was skewed and my ability was quite poor in gauging the effects my injury would have on my relationships with others. As much as I wanted and tried to contain the damage caused by my injury, I could not. The change brought about had not only affected the physical realm of my existence; it also transcended to disrupt my relational and social connections.

We made our way to the theater where the normal struggle of finding a place to park was negated as a result of my sweet new ride and handicap parking placard. “You're all welcome for the VIP parking.” I sarcastically announced. Silence. I thought it was funny, but apparently nobody else did, as the tentative and polite smiles surrounding me would suggest. I knew something was off. If what I said was funny, they would laugh. If what I said truly wasn't funny, I for sure would've been

made fun of for telling a bad joke. Both responses were absent as my friends silently filed out of the van as soon as the creaking automatic ramp hit the pavement.

We made our way inside the theater where Kristen paid for the tickets and I waited off to the side with another friend. While waiting, a towel fell off my armrest and onto the ground. A good Samaritan walked over without making eye contact, picked it up on my right side and handed it to my friend standing on my left saying, "I think he dropped this." I remained silent until he had walked away. I didn't know how to respond to the act. At first I thought it was fair for him to assume I had some sort of cognitive impairments.

I went on to debate this episode in my head throughout the movie, and came to conclude that his ignoring my presence did offend me. However, I couldn't figure out why, as I could not decipher his motivation: Was it because he thought I couldn't talk? Was he afraid that in addressing me he might worsen my condition? Did the wheelchair somehow convey a high level of fragility he didn't want to disrupt? What inspired all of these assumptions? Can this all be attributed to naïveté?

My confusion about how strangers now interacted with me continued throughout the evening. At dinner the server asked Kristen, and not me, for my order. I ignored the slight and ordered in a manner that was perfectly understood by the server, who appeared to be caught off guard. It was a mistake on my part by letting the affront slide. How do you call someone out on such a thing? The server's free pass had expired when she asked Kristen later in the meal if I wanted my drink refilled. I was outraged but remained silent. I didn't feel comfortable expressing that I was offended as I didn't quite know how to take ownership of my new identity.

Had I transferred out of my wheelchair into a normal chair would have I experienced any of the negative moments? While other explanations could be put forward, my read is this: because I did have the chair, I was treated differently and fell victim to the unjust stigmas that are associated with those in wheelchairs.

Things had changed.

My friends were apprehensive to start conversations or disagree with anything I said. Strangers treated me in a way that made me feel like every set of eyes were looking at me, and yet, simultaneously denying my existence. I longed for my therapists and nurses who understood that, on the inside, I am still a person who is worthy of being treated as an equal. Initially, they were the only ones who acknowledged that many of the unique requirements that accompany disability can be normal and should be viewed accordingly.

Hospital employees are charged with performing necessary tasks that a nondisabled person may assume are inherently awkward, uncomfortable, and indecent for both caretakers and patients. However, this type of care is necessary to maintain the health of the patient. More importantly they are completed with great effort to still attend to the individual's dignity. Experience and training aside, I thought it was odd that the nurses are able to do something that is incredibly personal and be less insensitive than a person who serves food.

I am insulted by this server. Ironically, being disregarded by a person who does not acknowledge my existence in ways that suggest that, because I am disabled, I must not be able to communicate by and for myself, makes the hospital showers feel like a warm embrace from a loved one. This night out was supposed to

be an escape from the realities of my hospital life, a chance for things to be as they were before I got hurt. This first trip out with friends had me reentering society thinking I was still the same person. I affirmed in short order that this was not the case and as much as I did not want to admit it, the worry my Mother had before we departed felt justified. It was clear that the damage done was in fact not exclusively physical.

With the loss of my athletic talents, my friends from sports teams have lost their tightest connection to me, my family has lost a cheap source of yard work and snow removal, and my fiancée can now only be swept off her feet figuratively. Even though I still felt like ‘me,’ necessary changes came about to reshape my social place and relationships with friends and family. Over time my injury had made it impossible for me to retain my former identity.

“Act I” of my life (as I have come to call it) came to an end in February of 2005. I was forced to reevaluate and reestablish the protagonist’s character traits to the audience. At first it took time to develop and practice my script for what would become Act II. In exploring my new approach, I met with failure in being able to express my new identity to others and was subject to interactions that were unintentionally offensive. As time has passed, I have found more and more of my on-stage chemistry that had been initially absent, but I am not all the way there. I have adapted and tried ways to mediate the fact that although I retain a large share of my past self, I am no longer the same. I wanted to retain parts of my prior self as I was comfortable with who I was, but felt the need (and was forced) to include my new circumstances as they brought value and depth to my personhood.

Current attempts to share these changes are often met with resistance and miscommunication. I have struggled and continue to struggle to sell my new-self to old patrons and new consumers. They are often unsure of how to conduct themselves around me as they can be overprotective (physically and socially) and overcompensate my needed assistance. I find difficulty in managing these situations. I can't seem to crack the code or find the balance between who I was and who I am. I continually grapple with what aspects of my being need adjustment, and which do not. In the process I encounter much difficulty in reestablishing myself and find difficulty in communicating what living with a disability means to an individual.

I assume all people who go through changes in life encounter this on varying levels, depending on the magnitude of their change. I wish I could take a break from performing for a while in order to implement *the* right method or approach, but I cannot. For I must not tarry, the show must go on.

Helpful Others

By year's end after my injury, I had regained a lot of muscle control and traded in my wheelchair for a sleek arm crutch. I was incredibly fortunate to gain some independence. I was now able to walk up stairs instead of having to search out a ramp or elevator which was great. However, the feeling of walking and blending amongst my peers took the cake. I was able to sit in a desk as I no longer brought my own seating with me to class. Visually I was normal minus a flashy accessory.

Despite attaining my new level of independence, the preferential treatment and unsolicited assistance continued. While standing up to submit papers to the

instructor I was often interrupted by a well-meaning classmate, "Here, I'll get that for you. You stay put." I appreciated the help, but it also made me feel like I was missing an opportunity to show off what I was capable of doing. I felt that, if I did not perform the physical acts, I would reinforce the idea that I was more reliant on the assistance of others. The distribution of worksheet piles during class is another notable phenomenon in which my ability to perform was limited. The piles of handouts would skip over me while making their way down the row, as a classmate would often go out of their way to grab one for me. Perhaps under the assumption that a person with a crutch can't pass an *entire* stack of papers. Instead of confronting the helpful others, I would idly sit by and let them reinforce their intrinsic motives.

By continually receiving and accepting these offers I was restricted in my ability to establish my identity. When accepting offers I was restricted in my ability to express myself as an independent person. Had I fulfilled these basic classroom functions by myself I would be able to successfully express my independence and ability.

Today, six years post-injury, at first glance I am free from any obvious markers that scream disability. The interactions I have with people I meet for the most part are fluid, free of the unease created by people feeling unsure of how to conduct themselves in the presence of a person with a physical disability. In essence, I feel able to hide my physical disabilities from those whom I interact with on a superficial level. Doing this shields me from the sometimes awkwardness in negotiating unwanted assistance. Even though those I meet today may not be aware

of my disability (which includes awareness for my potential need for help), those who are privy to my past still appear ambivalent of how to act around and communicate with me.

An example of this ambivalence is evidenced by my experience going in and out of doors and paying attention to how others communicate through the act of offering assistance. Doors can be very difficult to manage for a person with a physical disability, due to several variables (e.g. weight of the door or bulkiness of a wheelchair). Although it can be extremely difficult for an able-bodied person to fully comprehend the challenges presented by physical disability, most people seem to understand the added complications in negotiating doors. To understand the differences between the performances when disability is present and when it is not, let us first look to what entering and exiting a building looks like with an able-bodied population.

Watch any entrance to a building for a few minutes and you will see similar behaviors. A majority of the action will entail strangers walking through doors in the order in which they arrive, sometimes pausing slightly to pass off the door to the person behind them. In rare instances the first person will hold the door for a group of friends or even a few strangers who follow behind. Societal norms tend to suggest that one should hold and/or open a door for a person carrying an arm-full of items, on crutches, in a wheelchair, or really anyone who appears to need assistance. It is a helpful gesture that assists the recipient and offers a bit of altruism to the person who completes the deed.

Since my injury and subsequent rehabilitation I am, for the most part, grateful to the countless good Samaritans that have held doors and assisted in the management of my surroundings (especially entryways that do not meet ADA requirements). However, since my recovery, I have noticed a phenomenon that has occurred several times. It is extremely subtle and involves the physical performance of entering doorways.

For the many strangers that share a social space with me, the door performances described above are as regular and conform to norms as much as any other population entering a building. What is unique here is that, whenever I approach a door with persons whom I know to be knowledgeable of my injury—incidentally, one that no longer affects my ability to open doors—they typically make the effort to be the first to the door to offer me unsolicited assistance. If I make the effort and beat them to open the door, it is quickly followed by an offer to hold it for me, as they prompt me to walk through. Even though I have regained my physical ability, my disabled identity (the identity expressing that I require an abundance of assistance), still provides ‘perks’ that are now impertinent and antithetical to my sense of independence characterized within my re-shaped identity. Similar to my inaction in performing physical acts in the classroom several years prior (i.e. rejecting offered help and handing in my own assignments), my inability to act first (open my own door) denies me the ability to reestablish my physical abilities among those who know me. Each time I succumb to their offers I feel I reinforce their intentions and any attempt to stand my ground creates a

shared sense of uncomfortable miscommunication. Thus, I am complicit in my own entrapment.

Indeed, the communicative dance that occurs between an able-bodied individual and someone who is disabled is complex and confounded by those who are ignorant to the needs and desires of a disabled person (as well as the disabled persons who don't share their unique needs and desires). Prior to my own injury my interactions with individuals with disabilities was limited to sharing pleasantries and providing solicited and unsolicited assistance. I'd like to say that my failure to engage in deeper and more meaningful conversation with a disabled individual wasn't on purpose. Yet when reflecting back, I believe my ignorance made me feel apprehensive and uncomfortable, which lead to overcompensating others' needs and misguided perceptions.

Over-compensating the needs of a disabled person can unintentionally presume that a difference other than physical limitations is present, which is potentially offending. What differences are present between the able bodied and the disabled? Is it strictly physical or does it also extend to how they orally communicate with others as well?

I have learned a lot since my days of being completely oblivious to the complexities of disability. I have lived and continue to live as a disabled individual; it is a marker of identity that will forever be with me. I have developed a clearer idea of what my disability means for me and my social place. Through trial and error I have come to learn how I feel most comfortable when negotiating assistance. Consequently, changes in how I communicate with others certainly have taken

place. As much as I wanted to grip tightly to the person I was prior to my injury and never change, I have let go. The changes have not been easy to make or acknowledge, but to deny the transformation would be an insult to the self-reflection and effort taken to reassert my identity and presence.

Going through the acquisition of a physical disability is an endeavor that many people have experienced. Each case is extremely unique, as there are multiple variables present (degree of limitation, available resources, prior activity level, social support, etc). I wonder, are their changes similar to mine? How do they manage them? What makes it hard to establish one's self?

A Look Ahead

The study that follows seeks answers to these questions. As much as individuals with acquired disability would like to conceal their injuries to the physical realm, it is impossible, because physical ability is so ingrained in our social selves. That is, physical ability is firmly intertwined with how we add emphasis when we communicate. I examine how coping with disability affects one's ability to communicate in the same way they did prior to their injuries. By interviewing several people who have gone through the transition, I aim to discern a better understanding of what changes occur. I take a deeper look at a variety of cases in order to see what strategies are used in establishing their new selves. I can only speak for my own experiences with my own injury. By opening up the conversation to my participants, all of whom have acquired physical disabilities, I include perspectives and experiences that are not solely my own. Through this I hope to

capture what themes are common for those going through such life-changing adjustments and how they are executed.

This study has provided me with an improved understanding of the profound complexity of disability and how to manage the changes associated with it. My findings do not mean to be representative of *the* answer to navigating communicative change following becoming disabled. Instead, I hope to shed light and offer guidance to those who are going through the process personally and/or those providing the necessary social support to help those making the transition.

Rationale

According to the Christopher and Dana Reeve Foundation over 24 million citizens in the United States report living with a physical disability, and 6 million report paralysis (Reeve Foundation, 2010). Even though this is roughly 8% of the population, the general public knows very little about how a physical disability affects a person and how to communicate with those affected.

Through this research, I hope to bring awareness to any pathological symbols that hamper those with disabilities from being understood by others. By being knowledgeable of what potential obstacles they are up against in daily interactions with the general public, disabled individuals can assume a proactive role in addressing and overcoming the challenges. Accomplishing this, in turn, will foster more clear communication between both parties. For the able-bodied population I aim to bring awareness to some methods to challenge established schemas of how to communicate with those with a disability or handicap. By examining what has been argued in the field, I offer methods for adjusting misinterpretations of the

social environment (on both sides, able- and disabled bodied persons). In doing so, I hope that stereotypes, prejudices, and misinformation concerning what it means to be and communicate as a disabled person can be challenged and reconciled with more effective perspectives. May this project offer ways of understanding these phenomena that are present in the lives of those with physical disability.

Knowledge gained from the completion of this study will hopefully benefit disabled individuals by decreasing the incidence of being coddled, offended, or misunderstood. Ability is an important dimension in one's identity. Persons who acquire a disability must also negotiate how they are to communicate their identity going forth without their prior physical abilities that helped to shape their identity. This research simultaneously benefits the able-bodied population by creating awareness of what it means to be disabled, and offers an understanding of the identity and relational changes that occur as a result of a acquaintance acquiring a physical disability. Thus, I seek through my work to help minimize or prevent offending comments or faux pas in future communication.

The relevance of this project also extends beyond the realms of ability. The radical change in relational dynamics brought about by the acquisition of a disability is similar to other major changes that occur in short order. Marriages, new children, death, divorce, and a multitude of other life changes all alter salient variables of one's identity. Knowledge gained from this research can offer insight to how change in identity occurs following a significant shift in one's life.

Exploring specific communication phenomena that occur between the able-bodied and the disabled is not a new thread of academic inquiry. A popular area of

research examines the role of identity and face (how we analyze our social costs affiliated with our acts, through the loss or gain of face), and features a variety of different disabilities. Although my research is focused exclusively on acquired physical disability, material examined in the literature review (see Chapter Two) that is centered on other forms of disability can help to inform what is understood about communication between disabled and able-bodied persons.

I find this thread of research to be extremely important and central to gaining a better understanding of myself and the experiences I have had communicating with others. In taking a critical look at my experience in the field, combined with the reported experiences of others, I hope to develop a clearer understanding of what under-explored factors contribute to these occurrences. Reestablishing one's identity is not a simple process especially when the reason to change is forced.

Forced changes in my ability created a wave of emotions inside of me. Initially, when interacting with those who clearly had no experience in communicating with those who are disabled emotions were negative (offended, embarrassed, helpless). As I grew more comfortable the same encounters elicited feelings of humor, embarrassment for them (humor at their expense), and an opportunity to educate. Below I hope to bring attention to this range of emotions that ignorance pertaining to ability can create. Although some misunderstandings can create very hurtful and demeaning feelings, others are humorous to those with disabilities as the ignorance of able-bodied people can be highly entertaining. The amount of pride and dignity that those with disabilities possess is greatly

underestimated by a general public that is quick to judge a lifestyle more challenged as one that is inferior. This project aims to expose the communication difficulties encountered by those with disabilities and offer solutions to help show that although they are different they are certainly equal.

Plan of Study

The opening two narratives help to demonstrate a glimpse of what life is like while transitioning from able-bodied to disabled. It is extremely difficult to fully comprehend the litany of other associated challenges that are presented, communicative and physical, with the acquisition of a disability. However, by sharing these experiences I aim to show a descriptive perspective of what experiences one may go through while making sense of their new surroundings. In doing this I hope the reader is more prepared and knowledgeable of the differences that are encountered by the disabled.

In Chapter Two I review relevant literature on the topics germane to this study, and in doing so, further speak to the rationale for the project. I also provide research questions that guide this study, and describe the methods I use to explore my questions. Chapter Three highlights the research participant's experiences. I describe, analyze and interpret the various responses. In Chapter Four I offer a range of conclusions stemming from the evidence collected with my participants. I focus on the essence of the communicative changes, how they are expressed, and what difficulties are encountered in resolving them. I also offer suggestions for those encountering the communication environment and those looking to perform

further research. I end by reflecting on the benefits gained, as a researcher and as an individual living with a disability, through the process of completing this study.

Chapter Two: Making Sense of the Change Disability Brings

This research focuses on difficulties in interaction for communicators who have experienced physical disability. I approach this project by using data collected from interviews and questionnaires with participants who are members of the disabled community. The chapter that follows provides insight concerning the objectives of the project while also presenting a review of relevant literature, research questions, and methods (analysis, theoretical tradition, ethical considerations, and participants).

Literature Review

The literature engaging communication and disability is vast. Commonly highlighted topics include: social costs relevant to when persons with disabilities communicate with able-bodied individuals (Braithwaite and Eckstein, 2003; Goddard and Torres, 2009; Hart and Williams, 2005), how the disabled male body handles what Lindemann (2008) describes as “leaks”; and innate predispositions those with disabilities may face (Park, Faulkner, and Schaller, 2003).

Dawn O. Braithwaite and Nancy J. Eckstein (2003) study how those with physical disabilities communicate assistance, needed and unneeded, with those who are able-bodied strangers or new acquaintances. They investigate the frequency assistance is needed, the type of assistance needed, how both parties manage needed assistance, and instances when there is a failure to acquire assistance. From their data they surmise that physical assistance comes with a cost that is paid by

embarrassment, loss of face, and sometimes by being offended by unsolicited altruism.

Significant implications stemming from their study inform my project. For instance, disabled individuals are encouraged to engage in advance planning to minimize their social costs of requiring help and/or having to refuse help from a well intended stranger. Other considerations from Braithwaite and Eckstein's work encourage the use of occupational technology to allow individuals to be as independent as possible.

Braithwaite & Eckstein's (2003) study informs this study in several helpful ways. First, they draw needed attention to the social costs that are involved in advocating for assistance. Paying these social costs in the process of soliciting assistance is a fee that newly injured individuals are not accustomed to paying. Knowing the possibility that these costs are present has helped me focus inquiries during my interview on apparent changes from able-bodied to disabled.

Their report also highlights the propensity for unsolicited assistance as a result of individuals thinking they know what assistance is needed. They offer the finding that people are often quick to assume that, because people are disabled, they automatically need and want assistance. My research can use these concepts as they address how able-bodied individuals approach communication with a disabled person. Drawing on their work, I am more able in this project to understand some of the motivations that are common during communication between a disabled and an able-bodied person.

Sara Goddard and Maria Torres' (2009) research uses face negotiation theory's application to the problems that disabled students run into on a college campus and explore how the problems are resolved. Face negotiation theory believes one's culture and overall desire not to lose face plays an important role in how they address conflict. The participants of their study have a wide range of disabilities, visible and non-visible (e.g. blindness, cerebral palsy, heart condition). The study suggests that disabled students evaluate their faces and faces of others prior to deciding how to confront a specific problem. The researchers propose important insight concerning aspects of communicators' identities, and the ways identity plays an important role in shaping communicative behaviors. Participants report that evaluating their own face (identity) and the faces of others is important when deciding how to engage in the communicative environment. As my research is concerned with the transition process from able-bodied to disabled, using Goddard and Torres will enable me to focus on how these identity components are adjusted and managed as individuals take ownership of their disabled selves.

Goddard and Torres (2009) also argue that disabled students are most comfortable receiving assistance solely from institutions (e.g. college disability resource centers) which portrays the desire to save face. Face and identity issues are important to this project because they help explain potential changes in communication as a result of disability and the new desire to save face. I intend on exploring how my participants have navigated their need to attain help against the potential social cost of embarrassment.

Russell D. Hart and David E. Williams (2005) observe the relationships occurring between disabled students and their able-bodied instructors. Their findings suggest that, although intellectually similar to other students, disabled students can have negative effects on the classroom. Four roles were found to classify how the able-bodied instructors communicate with their disabled students: the avoider (kept physical distance, short with communication, appeared uncomfortable in the presence of student), the guardian (protective of student, lowered standards for disabled student), the rejecter (refused to take student seriously, withdraw from disabled student more than able-bodied students), and the nurturer (give disabled students the same chances, treated equally).

I would like to believe that some of the instructors talked about by Hart and Williams' research are isolated incidences; however, with several examples presented in how those with disabilities are misunderstood because of anxiety, I find it a problem that still needs to be overcome. The four communicative roles assumed by the instructors can offer support for how friends, family, and colleagues respond to a loved one's disability in varied ways, depending on their comfort with the person injured. Simultaneously, the groupings benefit the disabled by bringing awareness of potential categories that develop within professional and personal relationships. The added awareness of this miscommunication can provide insight to what skewed understanding is present and how it can be corrected.

The various efforts mentioned above put forth by the disabled typically seek a way to establish their identities, that is, to act in distinct ways to help convey a certain trait in attempt to fulfill some motivation through self-expression. Kurt

Lindemann (2008) presents a thoughtful perspective to view these efforts. His autoethnography uses personal experience with his disabled father and additional immersion within the disabled community. Lindemann highlights how the masculinity of disabled males is narrated through hidden and exposed “leaks,” which helps to establish identity. He posits “leaks” in the masculine disabled body to be both literal (incontinence as a result of the physical injury) and figurative (moments of displayed behavior that do not reinforce the traditional male identity, e.g. requiring assistance or physical weakness). After providing thorough examples of performances that capture the presence of leakage, Lindemann closes his account by reflecting on the motivations of those managing their leaks:

The picture on the opposite wall shows [my father] finishing a marathon, his face frozen in a look of determination as if he had something to prove to the world. Surely, his disability changed him some way, as did his sport participation. But is it fair to say he went from smiling, doting father to obsessed wheelchair athlete in an effort to contain the leakages of disabled body? There’s a gap in this line of thinking. (p.25)

Lindemann’s conclusion presents us with interesting questions concerning what his father's identity change can be attributed to. Was the devotion to wheelchair sports solely an endeavor he undertook in an effort to conceal leaks? Or was the new devotion free from intentions to ‘prove’ to the world he had maintained his masculine identity and simply a rechanneling of his passion from his former marathon days?

The questions that arise from Lindemann's work are important to the current study, because they highlight the complexity of motivations and attribution concerning disabled identities. For me, it certainly is narrow minded to think that every action post-injury serves only as a way to proclaim that one has not been defeated (i.e. to conceal leakage). At the same time one must be careful to consider the importance of managing leakage as motivating factors. While demonstrating the significance of leakage, Lindemann's concept of leakage reinforces the complex nature of the performances of the physically disabled as well as the need for research to approach the topic from a multilayered perspective.

The presence of physical disability does not only affect physical acts and oral communication. Justin Park, Jason Faulkner, and Mark Schaller (2003) explore how the presence of known disability plays a pivotal role with nonverbal messages as well. They argue the extent to which disease-avoidance heuristics influence interaction, while in the presence of a disabled individual. Guided by an evolutionary psychology approach (i.e. one that believes our behavior is heavily influenced by innate traits acquired through the process of evolution), their theory posits that, when able-bodied individuals are in the presence of somebody with a physical disability, they are prone to respond negatively (behavioral stiffness, anxiety, and discomfort). They suggest that this is due to similar visible traits shared between a physical disability and contagious and/or debilitating diseases.

If these subconscious communication patterns are present in this sense, the deck appears to be stacked against immediate acceptance of an acquaintance's disability. Moreover, the authors note that exposure is negatively correlated with

noticeable anxiety and that, over time, persons can overcome predispositions. Although these assumptions can be remedied over time with close loved ones, the issue would seem to remain as related to interactions with acquaintances and strangers. The dimension of avoidance present in this research is certainly in play during the readjustment phase of a disabled person's identity.

My research aspires to enhance our understanding of how society, the self and mind combine to produce effective communication, as well as investigate what symbols produce dysfunctional communication processes when disability is present. I hope to contribute to what has been done on the subject of communication with the disabled by exploring how those persons with acquired physical disabilities navigate their identity shifts. By analyzing what approaches participants narrate as most helpful, and those that hampered clear understanding, I aim to offer a clearer picture of how different significant symbols can sway interaction.

A unique aspect of this research is the focus on how persons with a physical disability negotiate their own views of identity, and the strategies they use to manage particular impressions with and for others. The obstacles and challenges in managing identity faced by the disabled is an uphill fight, because prior assumptions may be in play. The various steps taken, blatant and subtle, to aid in the social performances of disabled individuals in order to convey their preferred impression will be explored within this study. Knowledge gained will advance our understanding of the phenomenon and enhance our knowledge of the topic in general.

The research presented above illustrates several relevant threads of disability scholarship, research especially pertinent to communication. In doing so I have emphasized the importance of identity performance (and leak management), social costs involved with receiving assistance, and the attitudes and related behaviors others display when communicating with disabled communicators. With this insight I hope readers are more informed about this area of research which will provide a base to take in and interpret the data and analysis that I present below.

Overall, much of the current literature about those with disabilities tends to focus exclusively on how persons who have lived with and established themselves as persons with a disability communicate within their environment. My study aims to contribute to the literature by focusing on how the transition, from able-bodied to disabled, shifts communication patterns in individuals as they seek to establish their new disabled identity. I will also explore how they go about mediating the change and problems that prevent a smooth transition.

Research Questions

Q1: In what ways do communication patterns change between individuals who have acquired a physical disability, family, friends, strangers, and new acquaintances?

Q2: What communication strategies do disabled individuals employ to mediate their change in identity from able bodied to disabled?

Q3: What dysfunctional symbols are present that complicate or prevent clear understanding and communication to occur?

Overall, the three research questions will allow the analysis of the data to focus on the unique aspects that are present in those with an acquired disability (i.e. those needing a readjustment of identity) as opposed to those who were born with disabilities.

Analysis

This project is driven by Symbolic Interactionism (SI), a theoretical tradition that explores the influences of the self and social environment in shaping each other through communication. SI proposes that the 'self' is an important social object that is developed and shaped by the interaction with objects in their environment and other people. By interacting within a communicative environment, objects are created and given meaning.

An example of SI can be seen in how the identity of a new co-worker, let's call him Frank is established and molded over time as a result of influence from several factors. Direct interactions with Frank, personal interpretation of his ability to perform his work, and the opinions of others all work symbiotically to establish "what kind of person" Frank appears to be (i.e. a statement referencing his identity). As a result, "Frank" becomes a symbol for a myriad of various traits depending on your interactions with him (e.g. dependable, friendly, and loyal).

In this study I will be exploring the unique communication used by my participants in order to extract specific physical, social, and abstract objects that have become social objects used throughout the disabled community. The complexity of the symbolic meanings of being/interacting with a disabled individual

is immense. SI provides a frame that helps explain what forces are in play when these interactions occur and how they shape understanding for all involved communicators.

Carey (as cited in Leeds-Hurwitz, 1995) believes communication should be defined as “a symbolic process whereby reality is produced, maintained, repaired, and transformed.” This interpretation captures the working assumptions of this project and helps reiterate the formation of understanding via communicative acts. Carey’s concept of communication nicely informs this project, as it provides us with an understanding of the power of communication in creating the ways we understand interactions about disabilities and the identities constructed in those experiences.

Data Collection

The data I collected for this project occurred in two ways: completion of a pair of twenty statement tests and a 20-30 minute qualitative interview completed via telephone. Each participant completed the data collection process in the same way.

Prior to the telephone interview, participants were given an adapted version of Kuhn’s (1970) Twenty Statements Test (TST)(see Appendix II for this questionnaire) Kuhn designed the TST to measure various aspects of the self by analyzing the 20 responses of the simple question, “Who are you?”As the question is intentionally vague, much can be explored by the responses given. Two of the main ways to do this is the ordering and locus variables. The ordering variable believes

that identity is illustrated by the order in which one answers the question, who are you? For example if 'father' is written down prior to 'husband,' it can be surmised that they identify as putting more value as being a father than a husband. The locus variable interprets the test by seeing if one identifies more with easily agreed-upon markers (white, American, male) or terms that are more subjective in nature (strong, confident, admirable).

My project uses an adapted version of the TST, as participants completed the test two times. The first time, they completed the TST by recording their first 20 responses to the question, "Prior to acquiring your physical disability, who were you?" After a short break, they completed a second TST that recorded the first 20 responses to the question "Today, who are you?" The purpose of this approach is that doing so assists with trying to discover obvious changes in identity over time and offers a chance to consider how they occurred. Discrepancies between the two lists offer me explicitly stated changes in the participants that can be analyzed and discussed during the interviews that followed.

Thomas Lindlof and Bryan Taylor (2002) state that: "qualitative interviews are particularly well-suited to understand the social actor's experience and perspective" (p.173). The use of an interview guide allowed for participants to share experiences which are central to getting at the research questions. Interviews showed to be effective at eliciting significant moments that characterize the participants' communication shifts as a result of their disability.

The respondent interviews followed a semi-structured interview guide (see Appendix III). Lindlof and Taylor (2002) describe an interview guide as an approach

to interviewing that follows a course of groupings of topics and questions, but allows the flexibility to follow various threads of discussion that arise as needed. This interview design allows discussion to be focused on the successes and failures of their challenge to reestablish their identity without limiting responses (and questions). As the development of my interviews was not rigid, additional veins of inquiry could be explored as they arose. This offered dense responses and on-the-side comments that provided a more accurate description that otherwise might have been limited.

Respondent's unique experiences helped shape each interview. The interview guide that I used acts as a catalyst that was able to be fluid in following new paths depending on the answers given by the respondents. Probing follow-up questions were also used as needed to fully address the participants' experiences.

Prior to each interview, I reminded participants of their right to refuse any questions. I also made each person aware that a recording device was documenting the shared dialogue. By reminding them of their rights and the presence of recording equipment I made them knowledgeable of my intentions as a researcher and hopefully provided a comforting environment where responses were freely offered by the respondent instead of coerced.

After the initial data collection I transcribed the interviews verbatim and examined my notes to find specific ways in which members of the community came to share meanings regarding what it means to be disabled and other related subjects. From my initial analysis of the interviews I was able to enter the

supplemental interview stage prepared to explore deeper meanings and strengthen my findings.

After capturing the essence of the communication used within the community I will be able to achieve a fuller and more established understanding of significant objects. I think the data collected will help in offering a better understanding of commutative differences that the newly disabled experience.

Ethical Considerations

Interviewing human participants and assessing their responses in a qualitative way brings with it certain ethical issues that must be considered. As a researcher I am extremely privileged to hear of the experiences and perspectives of my interviewees, and have aimed to enact each aspect of this study's process in highly ethical ways. Two influential perspectives concerning ethics guide my approach.

Carolyn Ellis (2007) and Linda Alcoff (1991) speak to the power and responsibilities that researchers embody, as well as the importance of representing research populations ethically.

Ellis, an autoethnographer writing about relational ethics in the field, describes what she feels are required ethics prevalent to representing a given population. She reflects on major ethical oversights made over the course of her multiyear study in a small fishing community. During this study, Ellis engaged in behavior that blurred the lines between researcher and friend. The result created relationships that were not equal as she fully intended on publically sharing the

entirety of her personal experiences with members of the community without having to disclose anything about herself. She essentially disclosed 'the dirty laundry' of the entire town for her academic gain, which, in hindsight, she now finds damaging to their lives. Within her piece she uses this experience to explore the difficulties of managing relationships while acting as a researcher. She continues on to offer examples of successful and unsuccessful handling of similar situations that she has encountered.

Reflecting on her focus of the article she asks, "You can be friendly, but can you be a friend?" (p. 9). Researchers often get very close to their participants and discuss deep topics that usually aren't shared with random people on the street. Related dilemmas persist. If you are talking about such personal and important parts of one's self, does that make you friends? Or is it a relationship with unequalled power levels, as the researcher is not required to disclose anything of a personal nature?

In performing my research I worked to remain mindful of how my participants trust me (as a researcher and perhaps a friend) with privileged information that I should not take lightly. I do not wish to replicate a situation similar to the fishing community fallout that occurred as a result of Ellis' work. In doing this research I remain open about my motives as a researcher and not disguise my intent by simply saying I'm "a friend of the College" (Ellis, 2007, p. 6). Prior to conducting any data collection I let participants know who I was and what my intentions were. I feel the openness demonstrates a clear conscience and the

opportunity for my participants to feel empowered that their story will be told in an honest way that is representative of the material they choose to disclose.

Alcoff (1991) stresses the importance of acknowledging one's social location and place of privilege while representing a given population. In the conclusion to this essay, Alcoff writes:

The practice of speaking for others is often born of a desire for mastery, to privilege oneself as the one who more correctly understands the truth about another's situation... but this development should not be taken as an absolute dis-authorization of practices of speaking for. (p.29)

In this sense, representing others' experience is a position that should not be taken lightly. In my quest to better address my research questions I take on the role as a researcher who more fully understands the larger picture of my interview data. In commanding this role I must be careful as participants have trusted me with their recalled experiences in the disabled community and expect me to interpret them with respect for their trust. I may not fully understand or agree with the participants perspectives but that should not keep me from expressing my thoughts while speaking on their behalf. Her conclusion continues this thread summarizing the power held by the researcher and the importance for controlling bias over one's perspective while remaining sensitive to those who you speak on behalf.

My participants are from a specific marginalized population that is incredibly diverse in nature. "Physical disability" is a large umbrella term used to characterize persons from a variety of ailments and limitations. Ellis' work informs this study by reminding me to remain honest with my participants by creating an understanding

that although our conversations have included information that is personal in nature what we have discussed will be shared. Doing this created a mutual understanding that provided me with what I needed to help tell their story and offered them the knowledge going in that what they said would be interpreted, analyzed, and published.

The sensitivity that Alcoff stresses reminds me about my own work with this vulnerable population, and calls me to remain cognizant of the need to always try to represent my participants effectively and ethically, in ways that reflect their experience, and not just my own. It also motivates me to represent each participant's a voice within my study in a way that honors their individual social place and perspective.

Participants

In this study I interact with four very generous disabled adult participants. Participants for this research are individuals who identify themselves as being active (i.e. athletic) prior to the acquisition of a physical disability. I sought active individuals for this research because they have been forced to replace or accept an adapted portion of their identities as a result of their injury. Although each participant is physically disabled as a result of a SCI there is much diversity among their abilities and limitations. Participants agreed that they were comfortable and able to provide candid recollections of their transitions from able-bodied to disabled. There were no limitations concerning age (other than being an adult), type of injury, and time since becoming disabled within this study. I collected

demographic information to be able to better consider this information's relevance to identity (see Chapter Four).

This study is approved by the Institutional Review Board at the University of Wisconsin-Superior. In accordance with the IRB participants were recruited both through personal contacts and e-mails sent out from the Courage Center-Duluth (a nonprofit organization that specializes in adaptive activities). Actual names of the participants have been protected through the use of pseudonyms.

I informed all participants of the goals and methods of the study prior to the start of formal data collection. Informed consent was required from each participant prior to participating in the study (see Appendix I for materials pertinent to Institutional Review Board approval). All interviews occurred via telephone. For improved documentation and accurate transcription I digitally recorded each interview in its entirety. Initial interviews moved them chronologically from pre-injury (pre-transition) to injury/rehabilitation (transition) to post-injury (post-transition). Follow up interviews with participants occurred as needed.

Chapter 3: I'm the Exact Same Person I Was Prior, Except...

In this chapter, I represent voices of interviewees, persons who describe their own transformations from able-bodied to disabled, persons I feel privileged from which to have learned. I describe key aspects from each interviewee's response, person by person. While I do not extensively study TST responses, I draw on them when fitting to more fully consider the interview responses (see Appendix II for a complete listing of TST responses).

I choose to infuse my analysis of the data within each participant section in order to clarify and help explain key pieces of the interview responses. My intent is to describe participants' ideas in as much of a conversational style as possible. Although I am well aware of the fact that I am representing their voices, by providing significant portions of the interview responses I aim to provide ample space for my participants' voices to appear. Doing so also will enable readers to come to their own understandings of participants experiences.

Mike

Mike is a 20-year-old Caucasian male college student from northern Minnesota. Prior to his injury, Mike's TST indicates he identified as a "soccer player, skier, mountain biker, and other physically driven identifiers." He also identifies as a social and carefree person who is faith driven. When Mike was 18-years-old, he was injured during a skiing accident that resulted in a complete spinal cord injury on his 7th thoracic vertebrae. This classification of injury means that all movement and

feeling below his abdomen is affected. As it is a complete injury, currently there is no medical treatment that can improve his function below the injury level.

Today Mike identifies differently, in so far as a majority of his physical markers are not reported post-injury. This is not surprising as the physical limitations of the disability make it very difficult, if not impossible to fulfill those exact traits. What is surprising, though, are the types of responses that fill in the space left by the departure of the physical identifying items.

Initially his identifying characteristics were easily agreed-upon terms (e.g. skier). Post-injury his responses include characteristics that are more ambiguous: problem solver, occasionally filled with grief, realistic. Along with the shift in characteristics, identifiers that remained constant are now qualified in some way: “social (not quite as much as I used to but I’m working on it),” “Hunter (still working out the finer points).” The shift from identifying with physical characteristics to less concrete attributes, and the qualifying of attributes that were stated pre-injury, indicates that something more than just physical loss is taking place (similar changes are seen in the other participants as well).

Mike describes the prognosis of being in a wheelchair for life as “a total shock” that “sunk in slowly.” In describing his family and friends reactions to his injury he thinks “a lot of people tried to put on a strong face for me. You know, personally. Because the person in the bed obviously doesn't have a whole lot of extra energy to deal with other people crying around them. So, you know, I guess it has been hard on everybody and it was hard. I just wasn't always able to see to what extent it was, but I know it was.”

Some friends were initially hesitant around Mike as to not say something wrong: "I have been with a couple people who are worried about [saying something wrong or offending me], but most of my friends don't worry about it. We joke and laughed like we always had done. We didn't discuss [my injury] a whole lot."

When asked to describe what has changed in his social interactions with others, Mike states, "I'm sure lots of people worry about how they are perceived, but I worry about what people think of me. You know you kind of wonder when people are talking to you, or sitting by you, are they talking and sitting with you because they like you? Or they feel bad for you? I guess I have my own concerns or filters about how they perceive me. A lot of second guessing I didn't used to have."

The shift in social interaction that is created by the presence of a disability is similar to the ambivalence that follows other instances of sudden change (e.g. unexpected death of child, divorce). These instances create situations where those not directly affected by change are unsure of how to address the "changed" person. The act of the family and friends "putting on a strong face" is a symbol found within disabled communication. By putting on a strong face, they acknowledge the masking of their true emotions and communication with the disabled person. This phenomenon is not unlike how my mother feigned confidence in sending me out on the town. Although both Mike and I understand the potential purposes and motivations to put up a front when it becomes easily transparent, Mike feels "it can become offending that they aren't being real with you," a sentiment with which I agree. Similarly, an uncomfortable environment is created between communicators when his friends approach conversations with him on eggshells, likely out of a fear

of offending and/or directly insulting Mike. For me, this suggests an acknowledgment is present that something more significant than simply a physical difference is present and that things have shifted relationally.

These interactions lead Mike to report increased concerns regarding how people perceive him. For instance, when interacting with friends and strangers, he is unsure of their true intentions. The increased concerns can be helpful in determining who is being authentic and who is not, but it can also be very problematic. For instance, by being hyper-vigilant, Mike runs the risk of not effectively communicating as the distraction of second guessing and not trusting the other person's motivation to talk to him. This interruption may discredit authentic communication as a case of somebody sympathizing for him. However it is a nice shield to have in order to protect one's self from such cases.

Mike speaks to some strategies he uses to combat this problem. With his friends around whom he doesn't feel ambivalence, he reports they don't directly speak about the injury, and that they are able to joke and laugh as they did prior to the injury. "We were always able to have fun, it never feels weird. I make handicap jokes all the time, it's a good way to break the ice." Humor pertaining to the disability is extremely helpful in easing the tension. Mike states that he uses humor to dispel "the awkwardness that some people get around me." Time and exposure has also been something that helps ease ambivalence. "Once people realize that I'm still my wacky self it feels like things get back to normal." It appears, as Park, Faulkner, and Schaller (2003) suggest, there is a negative correlation between time spent developing the relationship with the disabled identity and feelings of anxiety.

The more time that his friends spend with Mike they are able to see that Mike is still a young adult human being and they begin to engage in communication that is similar to what it was pre-injury.

As I know through my own experience, wanted and unwanted assistance commonly becomes a part of everyday life for the disabled communicator. In speaking to the unwanted offers for assistance, Mike conveyed: "I guess in the beginning it was more of, in the first couple months, kind of a shock thing [that they'd offer], and it was more annoying to me not because they were asking, just because it was different and I didn't like it. But now it's different, I recognize that they are just trying to help. I guess now I don't feel the whole range of emotions, I just let them know that I am all right, [the help] is kind of expected at times so it no longer catches me off guard." This expressed difference characterizes a shift in the interpretation of how Mike feels others perceive him. He has gone from being shocked that people go out of their way to offer assistance to a position that comes to expect others to offer a needed assistance. It is also helpful to note that although the offers can be intrusive he views and welcomes the gestures as acts of people trying to do the right thing.

On the topic of needing to ask for assistance, Mike reports: "At first [asking for assistance] was really uncomfortable. You get used to it, if you are sitting somewhere and you can't get something at all, I mean even I have days when I'm too embarrassed, so I don't ask and I'll just leave. I figure I will come back later with some friends. I guess I sort of got used to it in some respect and in other respects it's still hard. And you know I just ignore it or I come back to it later. Over time you get

used to it. But now (brief pause), I guess it's still uncomfortable at times, I just say, 'Hey! Can you give me a hand with this?' Then I just kind of smile and If I get their attention I just kinda ask. I mean it's kind of a shock, you know, lots of stuff you never needed help for, all of a sudden you are getting help, and it's different."

"Even the fact that people tend to always open doors for you. It's really weird coming from the guy who always used to open doors for other people. Granted I still try to rush and open doors for other people just because it is kind of entertaining. I've raced people to the door in order to open for them. I know they are just being nice, that is okay and just fine, but they totally don't expect me to open a door for them."

When Mike encounters unwanted offers for assistance, he tries to remain patient. "I have come to accept it, I know they are just trying to help, and in a way it makes them feel better to help out. There are some times when someone will say, 'are you having a bad day?' It's just kind of irritating, because it's like this sucks. I'm tired of people running around and helping. As a general rule I try to look at it as them trying to help and have good intentions, and it makes them feel better and it's not a horrible thing all the time, but sometimes it's irritating."

Whether or not he accepts the assistance from others depends on what others are offering him. "It depends, with doors I really don't mind, however if it is with books or something that I clearly have, I'm more likely to say no I got it. [With friends and family] I made it clear right off the bat that I didn't want anybody to push me unless I asked for it."

Mike describes the initial overwhelming differences involved in navigating his environment following his injury. As his responses suggest, the more time spent performing his disabled self, his levels of feeling accepted and comfortable increase. However, he also reports instances where help is unwanted or unattainable because of the social risk. These realities limit him from attaining certain needs when he wants as he must solicit help in a way that does not compromise his self-worth.

This description of having to wait to get help from friends he knows, for me, serves as a vivid illustration of Braithwaite and Eckstein's (2003) discussion of social costs and Goddard and Torres's (2009) application of face theory to those with disabilities. In those situations he assesses whether or not the assistance received from the stranger is worth the risk of embarrassment and hassle of asking. When he is among friends he feels more comfortable (i.e. experiences less risk) in soliciting assistance. These theoretical perspectives also come to life in his reluctant acceptance of unsolicited assistance. Although he finds it irritating, by accepting, he feels that it will make them feel better about themselves by helping, and, in effect, he is able to avoid the awkwardness of turning down a "good" deed. The complexities affiliated with this negotiation of assistance, in turn, shape the ways Mike negotiates himself.

There's a way in which Mike's use of offers of help work to establish a new identity. By refusing assistance pertaining to the movement of his wheelchair, Mike effectively uses the parameters of his ability as a way to construct who he is and what he can capably do. By demonstrating his ability to carry his own books and be independent, he is also helping, following Lindemann (2008), to close any leaks of

masculinity that could result from being too dependent. Even though his retention of prior identity is reinforced through the performances of displaying independence Mike acknowledges an important change that has occurred.

The feeling of total shock that followed Mike's injury can motivate us to re-evaluate our perspectives on life. In my opening narratives (Chapter One), I speak to my ways of reconciling my formerly able-bodied self to what became my disabled identity. It certainly is not something that is easy or necessarily the same for each individual. Mike summarized his new perspective of the world around him: "Life changes anyways, I was always a kind of a cautious person which is kind of ironic, because I ended up this way. But after an accident and you feel something so deeply, you can tend to see, or I feel that I have, not that I fully understand what other people go through, but there's a lot of hurt in the world that I didn't see sometimes before having the accident." Through his own experiences he has been able to empathize and acknowledge the sometimes harsh realities of the world that we live in. This disability has forced him to take a look around at others whose lives have been affected by unplanned circumstances and realize a dimension of his environment that he had not given thought to prior to his injury. This is not the only change that he acknowledges.

When asked if he is still the same person, Mike responds, "In some ways yes I am the same person and I need to be reminded of that sometimes when I am feeling down. Sometimes it's hard to see past the other things that have changed to realize, you know, that I am still me, and I haven't changed. Yet in other ways you know, I am a very different person just because I've learned a lot and stuff has changed,

things are different. So, I don't really know how to respond except for saying yes and no at the same time really.”

Mike's response to the question at hand, for me, illustrates a position of ambiguity, similar to the one I had during my transition. I would argue that, although many things do remain intact following a spinal cord injury, as Mike stated, *things are different*. Mike's interview responses show some noticeable and definitive changes in his identity shaping communication patterns.

Mike's feedback helps demonstrate changes in how people engage in communication with him. For instance, the initial hesitation of friends and family, as well as the continued uneasy encounters with helpful others, all illustrate an engagement of communication that is different than prior to his injury. In addressing some of these obstacles Mike uses humor to establish his identity, “It's a good way to break the ice.” He also uses his assertiveness in carrying his own books and racing to open doors when with friends to convey his new self. Complications that he has encountered are spawned by helpful others and his own second guessing. His acceptance of unneeded assistance does him no favors in projecting his desired image. As does constantly asking whether or not a person he is communicating with is being authentic or engaging with him out of sympathy. Both are distractions that are potentially troublesome. Mike's experiences do a great job of reflecting what factors are present in the communicative environment of the disabled. Through exposure to his experiences we can gain a better understanding of the questions proposed by this research.

My interactions with Mike would show him to be truly a good guy in every way. I'm left remembering how, in several instances throughout our interview, he referenced how he still was his same "wacky-self" despite his injury. He leaves me further thinking about disability and personhood and how physical disability might take much, but certainly not everything. Some dimensions of who we are endure, and in positive ways.

Ryan

Ryan is a 21-year-old Caucasian male who is currently a college student in central Iowa. While attending a college party when he was 18-years-old, he fell backwards out of a second story window. The impact resulted in an incomplete spinal cord injury (SCI) at the 7th cervical vertebrae. This injury classification means that Ryan lost all function and feeling from his chest down along with a majority of his arm muscles. The designation of "incomplete" means that the spinal cord was not completely destroyed, leaving open the possibility for improved feeling and muscle control after completing intense physical rehabilitation.

Prior to his injury Ryan identified as a "friendly guy" who is "outgoing" and "loves to party." Similar to Mike's post-injury insight, Ryan still identifies through similar traits that carry with them some qualifications, as well as some new traits that help represent his identity. He reports being "still outgoing, but not as much," "new love for family," and "more thankful and grateful person, because of everyone who has helped."

A unique statement on Ryan's TST is that he "has no decency anymore due to [his] time in the hospital." This self-identification, for me, shows the lasting impact

that being a vulnerable patient can have. During our interview, he elaborates: “Yeah that, um, well when you have a million different nurses in the hospital. Fondling you, and showering you. All of your sense of decency has gone out the window. You really don't care what people see or do now like you did before the injury. It's just like, ‘well, you saw me do this before, so I don't even care anymore.’ I guess two years out though that has changed. I mean I'm not as exposed as I once was, and I guess I'm more comfortable with it, like my dad walking in on me in the bathroom, I'm fine with that. Like before [my injury] if my dad walked in on me in the bathroom I'd be like, ‘Hey! What are you doing?! Get out of here!’”

I ask, “So, it has become normal in a sense?”

He responds, “No. It is better, but definitely not normal. I can certainly rationalize that the things in the hospital were necessary and approached them with the best attitude possible. But, definitely not normal.”

Questions pertaining to normalcy come to be a recurring theme in Ryan's story. Through exposure to the world of disability, instances that would prompt extreme panic and embarrassment have come to be nothing more than common practice. Although Ryan does not yet explicitly characterize it as normal, certainly a paradigm shift has occurred. The shift in how one interprets these relational moments and establishment of boundaries is not completely a result of the injury. Nothing medically related to the injury necessarily makes you enjoy situations like this. Rather, it is a shift in perception of what those forced shared moments of intimacy mean to the individual. In my experience, I initially thought I was not a worthy individual, as a result of not being able to dress myself and the

'embarrassing' assistance that the situation required. Over time, through exposure to the realities of living with a disability, both Ryan and I are no longer ashamed of the needed required assistance. Experiencing the once invasive interactions repeated times, like many things, lessens the surprise as well as the stigma associated with the act.

Ryan's initial recovery and transition following his injury was eased as a result of his mother being a nurse practitioner who specializes in the treatment of adolescents with spina bifida and other spinal injuries similar to SCI. Her knowledge of the medical needs that accompany spinal injuries positioned her and Ryan well ahead of the curve in terms of the necessary ways of comprehending the severity of injury. Ryan reports that her knowledge, along with constant social support from friends and family, made his physical transition easier.

In the initial weeks and months following the injury, he reports his parents treated him the same: "When I got home my mom just, she knew what to do and she kicked my butt. She's like, 'I'm not going to be your nurse.'" On the other hand, his friends were different in the way they approached his injury. "Friends and everything, they wanted to be there for you at all times. And so, those relationships definitely changed... they'd do anything for me now. Unlike my parents who just said 'suck it up.'"

The experience his mother has had in her profession treating individuals with physical disabilities allowed Ryan to avoid many of the pitfalls that other families could experience. Her kick butt attitude was straightforward, honest and not veiled behind a 'strong face.' By addressing that there are significant obstacles

that need to be overcome and taking a proactive approach, there is an acknowledgment of the injury and its impact. This saves the process of putting up a false front and approaches the issues honestly. I address the relational changes between friends and the injured party more fully below, when discussing Greg's story.

Ryan says that humor played an important role in coming to terms with his new identity. Initially jokes were 'off-limits,' but after he was out of the hospital, his friends have been able to joke with him ever since. Jokes include things that do and do not pertain to his disability. He claims his friends constantly joke about his disability, something he now does not mind.

"We make fun of wheelchair stuff all the time, and I mean, it's no big deal. I mean everybody knows we're joking. Well not everybody knows we're joking about it, but those who need to know do. I have this friend who, just, he harasses me for being a cripple all of the time. And then, like other people when they see him do it they are like, 'Can he do that?' But, it's no big deal at all, I mean, yeah, I don't know."

Although the term "cripple" is viewed as a derogatory term by most in the disabled community, Ryan interprets it differently: "I don't know, if anything it is more of a motivation tool. If somebody calls me a 'cripple,' I'm like, 'Oh, I'm not going to be that way for long.' And [the term] just makes sure you strive and work harder. Other than that, I guess being in a wheelchair now (brief pause) gives me a lot more freedom to make fun of others in wheelchairs. (nervous laughter) I know that sounds really bad, but I mean those with our perspective understand."

As first mentioned in this project by Mike, humor is a great way to transcend the awkwardness created by an acquired disability, a view shared by Ryan, who reports he enjoys being “fair game and one of the guys again.” His interpretation of the term “cripple” is certainly unique. Drawing back on Lindemann’s (2008) concept of leak management, I would suggest that by viewing the ascription of that term as a chip on his shoulder, Ryan increases his effort to manage his leaks.

Ryan’s injury is classified as incomplete, meaning there is a potential for regained ability. As he is only two years out from his injury, the window for improvement is still open, but closing quickly. Depending on his outcome I would be very interested in hearing his perception of the term “cripple” in the future when he is unable to deflect its weight to the hope of a full recovery. My sense is that as he feels he is not destined to be in a wheelchair for life he need not feel any offense to the term. For him, currently the term’s application to him is humorous and temporary, akin to someone being picked on for having an ugly haircut. If he does not improve I am curious to know if the whole weight of the term will be accepted as easily as it is today.

Ryan’s disability has been able to provide some additional benefits for him that were not present prior to his injury. On campus he has been able to intentionally parlay his disability when applying for jobs and getting into courses he otherwise would not have gotten into. “For example, say I wanted to get into a class but it was, like full, I could just ask my [college] advisor and he will be like, ‘Yeah. No problem, we will get you in there right away.’ You can definitely do a lot of things

like that and get things I otherwise would not have gotten. And using it to your advantage is definitely helpful.”

Hart and Williams (2005) would classify this instructor as a guardian. In their sense, a guardian is an instructor who is overly protective of the students and lowers standards to provide excessive accommodation for the student. By providing a competitive advantage in enrolling to Ryan based on the fact he is in a wheelchair is meeting the criteria. Indeed, Ryan’s leveraging of his disability in this way can be quite easy with the help of a guardian, but also very problematic. Much like other examples of accepting unnecessary assistance, by taking the offer Ryan’s ability to negotiate his identity (independence) is compromised by gladly taking help that is not needed. Although Ryan benefits academically his performance reinforces the actions taken by the guardian advisor which will encourage holding those with disabilities to lower standards.

A distinction should be made pertaining to accommodations for students with disabilities. Sidestepping enrollment measures simply because an individual is disabled is not reason enough to provide preferential treatment. The advisor would be classified differently if the course in question was needed specifically because of reasons that accompany disability (e.g. needed to fit therapy schedule, only section offered in an ADA accessible room).

Ryan reports no issue about accepting physical assistance from others: “If somebody wants to help out, I’m never like a jerk about it. There’s some other guy in a wheelchair here who is just a complete asshole about things like that. If somebody wants to help me and I don’t need it, I’ll just be like, ‘that’s alright don’t worry about

it, I got it.' You know? It doesn't affect me in any way at all like it might affect some others in wheelchairs. [The other person on campus would respond], 'No! I Got It!'"

Ryan goes on to illustrate his methods of selecting others to ask for assistance: "If you want me to be very honest, it does not matter to me at all [who I ask for help] unless, the girl is very pretty or I have some sort of crush on her, allow me to clarify that, if she is pretty I will not ask for assistance. Otherwise male or female, it does not matter, and obviously certain scenarios would only be guys like lifting something for me that is heavy, you know manly things." Misogynistic undertones noted, this response is a perfect example of leak management in action (Lindemann, 2008). By searching for helpers who do not fit the parameters of his desired type, Ryan can keep up the illusion of his performance of masculinity and independence for those who he does find attractive.

An alternative interpretation of his selection is that he may be attempting to save face by sizing up the pool of helpful others prior to asking for help. Let's say he needed to be lifted up a pair of steps to gain access to a non-accessible building. By seeking out a muscular athletic male over a petite female for assistance he will improve his chances for success in achieving his assistance, thus reducing the need to ask several people (i.e. increase embarrassment).

In the years since his injury Ryan has regained varying amounts of sensation and muscle control throughout his body. Although he is still reliant on a wheelchair to go long distances, his ability to walk short distances with the assistance of a walker keeps him hopeful for continued improvement.

Ryan expresses excessive hope concerning his ability: “Ever since [the injury], having [someone] say, ‘you’re not gonna be able to walk.’ I mean, like, up until even today, just thinking I’m going to be in a wheelchair for, like, a very long time hasn’t really hit me yet...I know I am going to walk again someday. I’ve always felt that way, so it’s always been just sort of a temporary thing for me, at least in my head.” This response reflects what I alluded to about Ryan’s interpretation of the term “cripple.” As he states he feels this is all a temporary issue that hasn’t hit him yet. His current identity is reflected in his approach to his injury and I am curious to know what continued changes will occur as the reality of his injury soaks in completely.

Ryan has come to terms with parts of his disability and wishes others would understand that: “Just that because I’m in wheelchair doesn’t mean I’m not an ordinary person. I’m just like everybody else. I just can’t do the same things as everybody else.” Ryan’s phrasing of the prior response is one that was also mentioned by other participants as well as myself (see: title). It is a collection of sentences that blatantly contradict one another yet act as a great example of how elusive and challenging it is for one to admit change, difference, and disability/limitations. More in depth analysis of this symbol is found in the next section as it relates better to Sara’s responses.

Ryan reports having a changed perspective on life as result of acquiring his disability. “Looking at life, I don’t know, when you are not in wheelchair you don’t necessarily think about [ability] when you’re not directly affected by [disability]. Being in a wheelchair now, I guess you could say, it makes you have a whole new

view on, just like, the little things that people in wheelchairs got to go through every day. Like opening doors or standing up and reaching things, it's just, really opened my eyes to a lot of things that I totally would have never noticed before. And it makes you have a whole different respect for people who do go through this and have gone through this their entire life."

In closing our interview, I ask Ryan about a note he submitted at the bottom of his TST:

I am the same Person pretty much the only thing I can think of that make me different are a new respect and prospective [sic] on life, and the things I can't do because of a wheel chair (Run, Dance, stand up for long periods of time).

"Yeah I can [explain] that, what I really think about from my life before to after, the only thing I think that makes, I mean obviously, it's a huge difference, are the things I can't do physically. As in, when people tell me I can't do this and I can't do that. Obviously if it's something physical, I can't do it. But if you say something like, 'you can't take this class' or 'you can't live here', or something like that, it's something I'm not really going to stand for. It's really hard to find anything different. One way I have looked at it too, I was a Christian beforehand too and I had faith. After the injury too. The injury doesn't really affect me at all in that way and [my faith] was still the same thing. I didn't take it more intense or do anything else with it, so it was all kind of the same. I think it was just kind of a lot of the basic things in my life were too. I can also relate that to drinking as well. I mean I still like to go out and drink and have fun with friends. I'm not gonna let a disability affect that part of me."

Ryan's shift of identifying factors points to a new perspective on life nicely illustrated in the passage above. His sense of decency and perception of normalcy have certainly received an adjustment as result of his disability. In this way, by reestablishing himself within normal social circles, he embraces reestablishing his place as 'one of the guys' and the banter that accompanies this role for him. Also, his concise manner for which he approaches the ways in which he receives assistance, for me, also symbolizes a shift in his communication patterns, as well as a method that helps disguise his leaks. He acts in a way that is more reflective and self-aware of how his actions can be perceived by others. Knowledge gained from this new approach allows him to better manage his performances which allow him to disguise unmanly limitations.

Sara

Sara is a 28-year-old Caucasian female who is currently a graduate student in northern Minnesota. After a night out at the bar with friends when she was 21-years-old, she fell off an elevated patio, which resulted in an incomplete SCI between her 6th and 7th cervical vertebrae. Today she is incredibly independent and uses a manual wheelchair.

Prior to acquiring her physical disability she identified as a social person who was very active and very independent. She enjoyed going out with friends, long-distance running and camping. Today she identifies as a wife, mother, and graduate student. Similar to Mike, Sara's characteristics listed on her second TST (excluding the three just stated) are not as easily agreed-upon as the first list and require a

heightened level of interpretation. They include, I am: inspired, blunt, proud, creative, happy, independent, determined, an advocate, passionate, and outgoing.

Motivated by this difference, I ask Sara why there is such a large shift from almost exclusively having identifying factors that were nouns, to a list that was made up of by a majority of adjectives. She responds, "I don't know. I didn't even realize that until you pointed that out. If I had to guess, I just feel, that my life is richer and more meaningful than it was in the past." For me, the evocative adjectives she uses tend to personify this statement. The nouns used in the first list are more cold, detached, and meaning is easily agreed-upon. The adjectives found in her second list invite readers to dig deeper and search for meaning of what is meant by each identifier. The differences between her two lists are much easier to notice than those of Mike and Ryan. It should be noted, though, that Sara has had seven years to reflect and sort out the changes in her life as result of her disability. Thus, there is a way in which time provides a person with a chance to reflect and become aware of the personal changes that have occurred following their injury.

Sara's initial response to the physical limitations created by her injury was instantaneous and proactive. "From the very beginning, I'm not sure if I was in denial or what. I was kind of, all right let's just fix things and get on with life. I have things to do. I was pretty light about the whole situation, I mean, I guess, that's kind of my personality. Let's just deal with things and move on."

As she had more time to transition, she began to acknowledge the ramifications of her injury. "I guess some of the first things that I realized was what I did not have with my body anymore. I mean, not having any movement in my legs

and stuff. That I could not really grasp completely, I don't think. That was just because there was no movement. As far as my arms, I could do some things with my arms and not others and that really frustrated me.”

Sara speaks to the ways her family served as excellent social support following her injury: “I am the only girl in my family. I am still the little girl the family, even though I was 21 years old at that point. But, one thing I did know about my family was that this was not the first really big, you know, difficult event that they had gone through. I refer to my Dad as “my hero.” He can take anything that comes at him and finds a way to go through. Right after I graduated from high school my mom had a brain aneurysm, and so, I mean my family has been through something that is long-term and difficult, and stuff, so we just kind of got through [my injury] as well. But, overall I think, they were right behind me. I mean if I was ready to kinda push on through it, they were there. I do remember some of the times, I was on the mats [during therapy] and trying to wiggle around and do stuff. It was difficult for them to watch me struggle. I do remember that that was hard for them to watch, me struggle. They wanted to help and stuff. Otherwise they were right behind me ready to push forward as much as I wanted to.”

She also speaks to the ways her family attempted to offer physical assistance both during and after therapy sessions. “They would offer, or they would try but I was really, I was really independent and I was going to do as much on my own as I could. And even if I was struggling and even though on the mats and some of the stuff that I do--I mean I have permanent scars on my elbows and whatnot from ripping them open because I knew I was going to do it even though it might take an

hour. I do remember watching my Mom wanting to jump in and help. But a lot of that just was that she had trouble watching me struggle to do things. [My family] didn't necessarily go out of their way, I guess they'd try to, but they would just kind of follow whatever I put out there. Like I said, they'd help me with things and they'd offer, but it was one of those things that I said 'no, I want to do it' or at least give it my best and they would hold back." Making them hold back helped to establish her disabled identity as an extremely independent person, something that started for Sara from the get-go.

Her pointed communication of her expectations to her family about what help she wanted and what help she did not want helped to keep everybody on the same page. Sara's description of her family and social support is similar to that of Ryan in that they have experience in handling life-changing maladies. The experience in dealing with these serious situations helped to cut through some of the more superficial responses that were seen with Mike.

Today, when Sara does need assistance she reports having no problem asking for it. "I don't really have a problem going and asking someone for needed assistance. Usually I just grab someone, you know, 'hey can you back out my van?' [A common problem created when somebody parks in an access aisle leaving no room for the ramp to fold out.] Or other times, what was it, where like, when it is very snowy and the sidewalk is not shoveled like it should be. I will grab somebody and say 'hey can you give me a little push through?' But you know, the parking thing makes me more irritated than anything and I guess it depends where I am at. If I am parked someplace and there is an access aisle next to me. When I get out I am fine,

but if I go into a store and come back out of the store someone has parked in the access aisle, where they're not even supposed to park, I actually get pretty frustrated. I will usually ask someone to go ahead and help me. But with something like that I don't feel that I should need the help. Because if someone wasn't parking where they're not supposed to it wouldn't be an issue."

In this way, Sara's experience of disability creates frustration when her environment prevents her from being able to communicate her independence. As she mentions in the examples above, in a perfect world these moments that keep her from acting independently should not infringe on her ability to do perform independently. When people park illegally and snow falls it creates an added challenge to Sara's environment. One that Sara feels creates a negative reflection of her identity as she must be more reliant on others.

This reliance is reflected in an instance she recalled about when she needed assistance, but received help in a different way than what she expected: "I remember that I had gone shopping. Normally I will hang the bags, and put whatever on the back of my chair, on the handles back there. I then just roll out of the store and I'm fine. I was rolling up the ramp into my van and I started getting some legs spasms. I ended up arching my back and I rolled backwards out of the van and tipped over out of my chair. I never really got the chance to ask for assistance, because the guy parked next to me, he saw it happen. And he whipped his door open, and um, started screaming about how we needed help. Then another guy in the parking lot saw, he came running over. I found [the responses] more embarrassing than anything just because they made a huge scene out of it. I

remember telling them 'okay, it's really not that big of a deal. All we need to do is get me back in the chair. I'm fine, that's all I need.' and stuff like that. If I do take a little tumble if I am out of my apartment then I do need help. But I have no problem asking someone if it is something like that."

The two experiences above both serve as examples of how those who are not knowledgeable about the disabled community sometimes act in counterproductive ways. Someone parking in an access aisle and sidewalks that have not been cleared are inconveniences that happen all too often. As Sara's position suggests, they are problems that should not even occur in the first place and, thus, she is frustrated whenever she has to pay the social costs of receiving assistance. The response of the helpful others in the parking lot experience works against what Braithwaite and Eckstein (2003) advise. Instead of listening to the person who needs assistance and honoring their requests, these persons perform in a way that suggests they know best. Yelling around the parking lot for additional backup (which was not necessary) and picking her up off the ground, in effect, prevent the more ideal response: simply listening to what was being told to them. Should the helpful others follow the simple instruction to position the chair, so she could transfer quietly back into her chair, she could be spared the excessive embarrassment of the calamity that ensued.

An even deeper look into this situation allows us to expand Lindemann's (2008) masculine leakage, a concept he specifically links to men. It is clear to see that although she is not male, it does not stop Sara from managing leaks by trying to demonstrate how she is as independent as possible. Receiving unsolicited assistance from others is something Sara accepts rarely and reluctantly: "So, if I'm out places,

there will be people who will ask me if I need help. If it's to help with something at the grocery store, that's maybe on a higher shelf or whatnot, they'll come up and say 'oh, well I'll help you with that.' I'll say 'no, no, it's not breakable I will just knock it off the shelf with my armrest.' Or some response like that. Or there will be people that will hold open the door for me and usually if I see that they are going to grab the door, I will just go to the next door and open it and offer them assistance. 'Oh, no I got the door for you,' I say and they kind of give me strange looks. I mean, I understand that they are trying to be helpful. But at the same time, if I don't need that help? You know? I mean I don't view myself in a different way than anyone else. If the world was set up so it's, you know, so I can be able-bodied like that. That would be fine. Since it's not, I try to make it work as best as I can." Her methods of turning down an open door may transcend disability and challenge notions of chivalry. Her actions patch any perceived leaks created by her appearance/wheelchair.

It was at this moment in the interview that I knew that Sara would be my most outspoken interviewee. Her description of turning down assistance in the grocery store aisle is courteous and respectful to the person who offered the invitation. The other example she offers is quite different and is something I wish I could see in person, in order to see the reaction on the helpful other's face. As I too have lived through in my experiences, the acts communicated during the process of going in and out of buildings are very quick and oftentimes lack the presence of oral communication. The process of helping someone open a door takes only a second

and commonly is performed with the motivation of assisting someone, disabled or not.

I believe the best way to discourage assistance is to verbally make a comment before they go through the trouble of opening the door. If I am not in time in heading them off, I walk through the entrance thanking them for their simple gesture. The three other participants also support this view when receiving simple assistance with doors. Most people usually do not need to go out of their way to help hold the door for someone in a wheelchair as they are also using the door. The other participants and I are also grateful, even if the helper needs to intentionally go out of their way to open the door as the argument is not worth the brief and minute assistance provided. I digress.

Sara further exemplifies what I see as a 'non-shrinking violet' status in the way she handles assistance with doors. For instance, as she wheels to a different door, blatantly ignoring the offer provided by the other person, in effect, she breaches the assumptions that might have led the, perhaps, well intending person's gesture, and in so doing, further asserts herself as an independent person. Her bold approach to navigating the scene would seem to be extremely effective, and not only demonstrates her independence on her own time, but also embarrasses those who make a gesture that might come across as providing unwanted help.

In doing this she risks collateral damage by assuming she knows the other persons' motivations. People hold doors for able-bodied strangers all the time, and for various reasons. To make the assumption that every person who holds the door for her is doing so with the motivation that Sara isn't capable of doing so herself (i.e.

out of sympathy or pity) feels, to me, to be just as unproductive as the assumption that all people in wheelchairs need help.

When Sara extends the olive branch to strangers, she uses humor to help break the ice: "I understand the seriousness of my injury, but at the same time, I'm pretty lighthearted about the whole thing. I make jokes, and it's not because I'm uncomfortable. It's just, you know, it's that's kind of the way I deal with it. I am pretty open right from the beginning. I will come rolling in and make cracks about how people there should watch their ankles or something. A lot of it is I just put it out there, that aura that you don't need to treat me like a little baby. I just kind of put that out there, like right away and I have found that it just tends to put people a little bit more at ease. Just if I project that right from the beginning, that this is who I am and this is going on. I do use humor, but I guess initially, I did have a little feeling of being on eggshells that people thought they needed to be careful around me. That feeling. That kind of irritated me." The insight here, though familiar, warrants a bit of explanation.

In this example of how Sara has come to navigate her social interactions, she reiterates what already has been stated above about the uses of humor and its effect on individuals who were initially uncomfortable in the presence of disability. Mike uses humor to reassure family and friends that the disability did not take his wit. Ryan described using humor to reestablish himself as one of the guys. Among other purposes, Sara uses humor in a way that calms the anxiety of those whom she does not know in order to challenge their initial perceptions.

My time with Sara also has made possible additional insight concerning major misconceptions about those with disabilities. She reports: "A lot of the stuff I have seen is that those that have disabilities, they just can't, there are things that we can't do. Or there are things [where people say,] 'you won't be able to do this or that.' They don't realize the fact that, you know, some activities and whatnot, maybe we can't do them in the same way that we did previously, but that doesn't mean we can't. I mean I have pictures and stuff that I have gone waterskiing. And I have had people, 'There's no way you can go waterskiing,' and I'm like, 'Well, what do you mean? I have done it so obviously I can.' It's just, maybe I have to do it differently. Or I have had, when I got married it was something that others were like, 'oh my gosh I can't believe it!' Well why not? Come on, people get married every day, what would be the big deal with me getting married? You know, it's things like that. Where it was maybe more taboo, but I don't know, for that stuff that going on years ago. But I'm like, 'It's 2011, things are changing.'"

Sara's insight here wonderfully captures what can be common reactions by people not familiar with the realm of disability to hearing accomplishments of disabled communicators. Of particular importance is the point about her friend's response to hearing that she has 'water-skied.' In actuality Sara participated in adaptive waterskiing. Although modified from traditional waterskiing it does not make it any less of an athletic feat, simply not the same activity captured in the standalone term waterskiing. The excluded "adapted" creates a miscommunication for both parties.

Granted, if a paraplegic told me that they water-skied in the traditional sense I have every right to show surprise and/or seek further clarification. Waterskiing requires the same muscle groups and talents that are required to successfully ambulate. Therefore, if somebody who is unable to walk is able to water-ski, it is a pretty significant accomplishment. On the other hand, Sara is frustrated in their inability to accept that a disabled person has water-skied. The miscommunication occurs as the definition of waterskiing is being viewed in two different contexts. Sara believes that adapted waterskiing is just as challenging and, therefore, needs no qualification by mentioning that some of the characteristics are different. Her friend, on the other hand, has no other interpretation of the sport and fails to realize that Sara has this perception.

Sara touches on a variation of a common phrase often used by disabled individuals: "I can do the exact same things I could do before my injury, just differently." [Note: a very similar phrase is used by Ryan in his description of what he wishes others understood about him]. In this case, Sara states that she can water-ski to her disbelieving friends as she did not qualify the statement. Adaptations of sports equipment, eating utensils, and physical methods for accomplishing life's daily tasks have become realities in the lives of the disabled. As it has become reality adapted items have become the norm. The result of this is that definitions of various symbols are different in the perspectives of disabled (e.g. what others may call an "adapted spoon" becomes "spoon" to a disabled individual similarly "adapted waterskiing" becomes just "waterskiing" as adapted sports is the norm).

Another example of this is the process of getting into a car. An able-bodied individual can go from house to the driver's seat in a few brief steps (leave house, unlock car, open the door, sit down). A disabled individual has additional steps (leave house, unlock car, put down ramp, enter the car, transfer from wheelchair to the driver seat). In the end, both persons accomplish same goal, even though they were performed in different ways. To say that one can do the same things, just differently, is unclear and perhaps disingenuous. The physical limitations prevent the disabled individual from doing 'the same thing' (entering a car door without a ramp, or waterskiing with two different skis while standing). However, ultimately, both people got into the car and both people received enjoyment from the athletic challenge of gliding across the water while being pulled behind a boat. A more concise phrasing of the expressed idea would be to say, I can accomplish the same things as I could prior, just differently.

Although there is a sense of sameness over time regarding communication and identity, Sara's experience also suggests specific ways in which she's changed: "I am very similar. I mean, I am still as outgoing, you know, as I can be. I like to go and have a good time. Um, but I guess I am more, almost more, independent now just because there's a lot of those you know misconceptions that people get, of you can't do this or that, and I'm going to make sure I can do what I can on my own." Sara continues on to credit her disability with helping to see and achieve her own potential.

"Then I guess I am a lot more of an advocate. Not only just for myself but for other people. I guess a lot of it is just I am more of an advocate than I was. I get out

there and let people know that—yeah these things happen but you can go on with life. Also, I think of myself as more comfortable now post-injury than when I was before. It is just, I have found certain things about me that I didn't even know that were there prior to being injured. A lot of it, I think is just a strength that I didn't know that was there and stuff. So, I think as a result, I realize a lot more of who I really am and who I want to be since I've been injured.”

Holistically, for me, Sara’s interview speaks to clear efforts at negotiating identity as a disabled individual. All her communication tends to foster a consistent message, which helps others perceive her as an independent and capable individual who can overcome obstacles and in turn, disprove any stigma presented to her regarding disabilities. At times, her methods may be overly explicit, but they succeed in establishing her identity at any cost via her performances. Whether or not others interpret her identity as she wants it to be is left unknown.

As an individual with a disability I was initially taken aback by how she treated those who questioned her abilities. In the management of my own disability, I would never think to insult somebody who offered me assistance, again likely in good faith. As a researcher I feel I can understand that this is her own way of handling her situations and her identity. These methods may not be overly friendly, but they seem to succeed in Sara being an authentic person. In this sense, I leave my conversation with Sara feeling pretty empowered by options for performing that might not originally have been available to me.

Greg

Greg is a 48-year-old Caucasian male who is the current Chairman of a foundation focused on educating and raising funds for spinal cord injury research. Prior to his injury he was an up-and-coming regional CFO for a well known wealth management company. He shares that his identity prior to his injury was known for his integrity at his place of employment. His ability to work hard, play hard, and his height all helped to make his presence known and allow him to command attention.

Greg was injured while mountain biking with his brother in Colorado in 1995. He suffered a complete SCI on his 3rd and 4th cervical vertebrae, which left him paralyzed from the neck down and reliant on a ventilator. Today he identifies much differently. He still has his honesty and integrity, but believes he isn't able to work as hard as he once could, as a result of the disability. Interestingly, a unique shift in identifying factors on the TST was his change from "I commanded attention" to "I draw attention." This difference, for me, highlights the vulnerability of those with this sort of a visible disability. As a tall individual prior to his injury, Greg could actively manipulate his environment in order to receive or deflect attention. Drawing attention is much different as one cannot control the sort of attention that is received (I more fully discuss this extra attention below).

As a result of his many years living with his injury and working for the foundation, by far, Greg shows the most developed and introspective insight, when engaging his answers when compared to all other respondents. This allowed me, as interviewer, to simply let him speak of his experiences and perspectives with minimal prompting. Given the richness of his insight, below I take a sizeable step

back in terms of representation, so that Greg can walk you through his experiences with minimal interruption.

Greg reports that, during the transitional phase of his rehabilitation, “the greatest struggle was figuring out how to visualize happiness while being in the midst of the situation.” Luckily his strong social and financial support helped to ease what otherwise could have been a more bleak and dire situation. “[My friends and family] were incredibly supportive. I had a family member present 24/7 for probably three or four months after my injury. They were encouraging. They were able to do whatever it took to provide a life for myself. They never hesitated as far as supporting and giving me ideas and hope for the future.”

Greg believes that his new situation definitely had an impact on his relationships. “I became a person that was completely dependent, after being a person that was extremely independent. That dependency puts a very different spin on relationships—particularly with family members because there's not an even give-and-take anymore in the relationship. You have one person that is constantly asking and you have another person that is constantly giving. And so, while they are there and are happy to help, it just puts a lot of strain on a relationship when it is so uneven. In that way, the person that is entirely dependent gets very tired of having to ask all of the time. [He or she] has to gain patience and try to ignore the little things that are wanted, because they are asking for things all the time. So you always have to assess if it is important. Is it something I can wait for? Is it something that I can just forget about?”

“I really try to ask myself when I have a need arise. In my mind I try to really ask myself, do you really have to have this right now or can it wait? Do you really need to have that itch scratched or can you ignore it? You know, that's still something that I do on a frequent basis. As those needs arise I try to always ask myself if it's something that I really have to have someone get up for. I realize how stressful that is on the other person and I try not to burden them anymore than I already do. I will also say that I don't use the word burden in a pitiful way. It's just I understand the dynamics of it. If I was on my feet and someone was asking me to do something for them every 10 seconds, it would get a little annoying after awhile. I understand that dynamic and I try to be as sensitive to it as I can.”

“Another way it plays out is that I have a wife and an assistant who help me out, so part of the answer to that question of need and can it wait, is that do you have to burden your wife with this one? Or can it wait for tomorrow when your assistant is going to be there? And so that's one of the ways that I try to manage needs”

“On the other side of the relationship you have the person who really wants to help out the dependent person, and despite that love and commitment, they are, after a while, they get tired of people asking all the time. And it is just human nature that they would do so because it is very constant and a heavy burden to have somebody do that. In that aspect it really changes the dynamics of relationships.”

“The corollary that goes with the relationship changes is you're suddenly limited in the number of things you can do with friends. Prior to the injury you could do all these activities. After your injury, it really limits your ability to socialize with

friends. There's one other aspect, of the change to relationships that I was going to mention. And that is very common to all tragedies not just [spinal cord injury], is when human beings go through tragedies together like that, it tends to strip away a lot of, of the uh, much more unimportant concerns that existed in a relationship. When you start to converse and deal with issues at a much deeper level, I think there are positives and negatives to that. It really focuses you on the things in your relationships with others that are important and you're more likely to dismiss those issues in a relationship that are not important. At least at first, over time relationships tend to normalize somewhat and you can still get back to the silly things in a relationship that people argue about at times.”

The thoughtful and thorough manner in which Greg recounts his experiences allows a clearer picture of how he and I believe others like him, approach communicating with others post-injury. Additionally, his contribution underscores the complex impact the transition can have on relationships. Greg reports that, as a result of his dependency on others, the dynamics of his relationships are heavily skewed, because one person is always giving and the other is constantly asking (I understand this point, but tend not to fully agree with the one-way nature of giving and taking he describes. After all, I am fairly confident he is able to provide emotional and other forms of relational support). The technique in which manages his high level of dependency is interesting and important to describe.

Prior to his injury Greg would have no issue asking his wife or friends to do him favors. However, as he has more demands for physical assistance post-injury, he is forced to analyze the social cost associated with having to ask for his desired

assistance. (e.g., added strain). His evaluation of whether or not something is worth asking for from his wife, versus what is worth asking for from his assistant for, to me, suggests a heightened desire to ease the burden on his relationships that he values more. By actively prioritizing his needs he communicates his empathy for those who do so much for him, by respecting their own limits to offering assistance. In doing so, he also conveys a message acknowledging that he understands how frustrating it must be at times.

An additional relationship change Greg suggests relates to the strengthened bonds with friends across the board. In this case, the presence of a physical disability helps to bring perspective into what is important and what is not in life. In comparison to the tragedy related to disability, the trifling issues that many relationships commonly suffer are seemingly unimportant.

Speaking more specifically about friends, Greg states, "I think you discover a lot about the strength of friends and relationships when you go through something like this. From my conversations with other people [with SCIs] it's fairly common that you lose some friends who thought were good friends. But, you also have people who you thought were just casual friends who will really come to your aid and support. So the first change is [that] you find out who your friends really are. But then amongst those friends the dynamics change a lot because all of the things, or many of the things, that you used to do to socialize, golf, going out, and having a drink, whatever it may be, are either impossible or so much more difficult, that a lot of that isn't an option anymore. Conversations become much more, either on the

phone or you set up a time where you sit in a chair and shoot the breeze with somebody.”

His mention of the changing dynamics between friends is particularly insightful with respect to how many relationships are typically dependent on shared physical activity. The injury creates physical limitations that narrow the number of places and ways that communication can take place. For instance, in my experience, by suffering my injury, I lost the tightest connection to my teammates, my contributions to the family via my yard work are limited, and I am restricted in being able to express intimacy with loved ones. Greg's disclosure that the location and medium in which the conversations are held is extremely powerful. The overall experience of having a planned phone call is much different than a night out on the town with friends or the bonding that occurs during a round of golf. In not being able to participate in these relationship-building activities, the real strength of the relationship is exposed.

Greg's injury requires a higher level of dependency on help from others. This may account for why his perception of helpful others is so much different than Sara's. Seeing this distinction, I ask him if he ever has encountered a situation where a stranger is overly helpful when offering assistance. “I caution on using the term ‘over-helpful.’ The situations you described, about moving a chair or opening a door, that help might be automatic. I don't find it to be overly helpful. I just find it to be a gesture of kindness. They are just trying to help and it doesn't bother me in any way at all...ever.”

“The reason I caution about the word over-helpful...there are times when people do things that are extremely patronizing. They will assume that, because you're in a wheelchair, that you also can't talk or have any brain function. So they won't make eye contact. They will talk to my assistant, even if I answer the question that they asked. I will answer it and then they will continue to direct the questions to the assistant. Or they will, you know, they will do things that I guess that would suggest that my mental process is more of that of a child. When they recognize that there is more, they still don't know or adjust how their dealing with me. So there is a point in which it can be negative as far as being over-helpful, but in most cases when somebody does a gesture of trying to be helpful, whether I need it or not, I find it to be very kind on their part and it never makes me feel bad in any way.”

“I understand that people are very uncomfortable with a person in my condition. They are nervous, they don't know how to handle it probably because they have not been in that situation before. That nervousness I think actually stems from concern about insulting me. Ironically, sometimes they insult me because they're trying not to. I think most people haven't been in that situation before and they don't have any idea how to handle it from a social perspective. As a result I go out of my way to try to make people feel comfortable. I take the lead in the conversations. If it is somebody that I see is quite nervous I try to, you know, joke around with them in some way. Humor is a great tool. That way they recognize that there is no need to be nervous and that I am not uptight or easily insulted. But sometimes it works and sometimes it doesn't.”

Greg's ideas offer valuable insight both in their own right, but also as ways that interestingly interconnect with others. For instance, the patronizing actions and ignorance others have expressed towards Greg are similar to: my interactions with the waiter and good Samaritan, the insistent offers that Mike receives in class to carry his books, and the hollering gentlemen in the parking lot that Sara encountered. Each was trying to do the right thing in their eyes. The irony described by Greg that involves the many people trying so hard not to offend that they end up insulting a person with a disability is spot on. As we have seen their efforts were not exactly the best thing for the situation.

Greg essentially attributes the rigidity and nervousness of others to the fear of offending a disabled person. This perspective is one that directly challenges what is put forth by Park, Faulkner, & Schaller (2003). I believe it is important to consider that the metacognition that occurs in others could be responsible for the uncomfortable social environment as opposed to it being strictly a biological reaction. If this is the case, education about disability and exposure to those who are disabled could ease the difficulties involved in making the transition from able-bodied to disabled.

Greg offered two tips that he would suggest for those wanting to be more knowledgeable about how to interact with those with a disability: "One is a short-term fix. It is to just tell people to deal with people with disabilities exactly the same as you would deal with someone else. If they, the person with a disability, take offense to something you've said, or some way you've acted, then that is the problem of the person with a disability, not with you. So don't worry about it. (Brief

pause) Look, there are jerks in wheelchairs. Just like there are jerks in the regular population. If you say something to a person in a wheelchair and they respond to you like a jerk, it is probably because they are a jerk. Not because you said something wrong. That's the short term fix."

"The long-term fix is education, beginning at the elementary level. Teach acceptance. Have exposure. I will go to my kid's school, and there is a lot of staring, but I don't begrudge that at all. What I see with the older elementary kids, they are extremely courteous. They offer assistance and seem to be quite comfortable doing it. I believe that it is because of what they've been exposed to. There will be a lot of benefit to people with disabilities as this generation grows older."

"Some are curious and they ask a lot of questions. Sometimes I see kids begin to ask questions and I will see the parents begin to scold them to not be so intrusive. I stop the parent, and I say 'No. That's fine. They can ask whatever they want.' That's just another way to deal with it as you would with anyone else."

The actions taken by the restrictive parents are other moments that help to emphasize the self editing that people may do in the presence of disability. Young children are extremely curious and have had multiple television shows highlighting some of the darndest things that they say. I feel that the parental interventions that occur during these phenomena are motivated by the fear of what offending comment might come out of their child's mouth. There are a plenty of questions that can be posed focusing on the adaptive equipment that are used by the disabled. Each question has an answer that helps to convey the identity of the respondent, but this

knowledge is not shared if the question is not asked. Greg put it succinctly, "That's why we ask questions, to learn. Why restrict that learning process?"

Greg has learned an incredible amount about life with disability through immersion in the community and his interactions with other disabled individuals. As a result of his injury and his experiences he reports feeling more aware of the world around him. When prompted with the question of whether he believes he had changed following his injury, and in what ways, Greg shares, "For the most part I would say that I am still who I was, with the caveat for now of excluding the physical aspect. It took a while to get back to that, because there is so much feeling in the short term that you have to go through. The whole grieving process returns the view. Otherwise I would also say that there are a few differences. I do tend to converse with people, at the appropriate times, at deeper levels. I don't think I get caught up in the little things as much. I have an infinite amount of more patience that I used to not have, just because that's the need for survival. So I think a lot of the traits are the same for me, but certain things could have gotten accentuated because of the new situation that I was cast into."

He further speaks to the changes he has experienced as a result of his inability to perform in a very physical world: "There is a significant difference in the physical aspect. I think that those physical differences are still a very important part of who a person is. Oftentimes I'll hear a [friend] say, 'Wow, you're the same person you were before,' and I always respond to them 'No I'm not.' Oftentimes I use the analogy of a three-legged stool, you have your mind, you have your soul or personality, or whatever you want to call it, and your third leg of the stool is in fact

your physical presence, the person I was before had all three, [the person I am today does not]. The way you interact with people includes that physical presence whether it is just visually or through physical contact with someone. That is part of who a person is, so a disability changes that so dramatically.”

Greg’s insight here speaks to reinforce the idea that change occurs regardless of how unaffected the mind and personality are as the third leg of his metaphorical stool is missing. I would continue his example by arguing that a shift occurs in the mind and personality in order to compensate for the missing support. These shifts are mediated through the changes in communication patterns (e.g. navigation of assistance, relational dynamics, and worldviews). Also, much like a two legged stool, the result is a fluctuating wobbling identity that is in search of stabilization.

“As what happened in my case, it changes the way that the people react to you. It changes the way that people perceive you. And I guess, it also changes you in a way that you can't interact with people. A simple example is, I can't give them a hand shake. That's a very real look at that. Shaking hands is in fact a very intimate way of hand contact to greet somebody. When you don't have that, that's definitely a loss. I guess I would just throw in that we can't completely dismiss the impact of the physical changes there are. There is another degree of your disability. There is a dramatic physical difference in the changes with relationships with people. I think a lot of people overlook [the impact physicality has on our identity]. I don't know whether they are attempting to overlook [the impact] in order to make a statement about how the disability [won't damage our] relationship, or whether they never

stopped to consider that it will change things. But yeah, it makes a dramatic difference.”

Oftentimes friends in this situation are reminded of memories from the past where they sat just talking to one another, able-bodied person to able-bodied person. Post-injury these moments may seem identical to the original relationship. After the conclusion the able-bodied friend is able to leave and go on performing their capacities as usual while the disabled friend must continue to live within their new reality that cannot be changed or ignored. Oftentimes the overwhelming question of, “what if?” surfaces in the back of an individual's thoughts.

“If given the chance to go back prior to injury, if we play that little mind game that I'm sure people do, I would choose not to, because I have had two children post-injury. If we go back in this mind game, I lose my kids. The hardest thing about having the kids in my situation, although I recognize that I'm extremely lucky to have them, is that I can't touch them. The person I was before was very physical as far as relationships go... [I would give] hugs that would lift people off the ground as a result of my height. [Going from that to being] forced to not be able to even initiate physical contact with my kids is very difficult. It also changes who I am with them now. They don't know that there is a change because they have seen nothing else. But it is a lot different than how I would've responded to my kids, if not in the situation. So yeah, that physical difference is a big difference and its impact on relationship.”

Greg's contribution to this project is immense. His 16 years of experience living as a disabled individual have enabled and called him to go through what he

calls “the complete grieving process,” a realm of experiences other respondents may not have completely finished. For sure, as this process might be one that spans the lifetime, perhaps Greg is still working through it as well. Nevertheless, from his responses we see many instances in which he has adjusted how he expresses his identity through communication without his physical presence.

Greg finds greater depth in the relationships he has today as he engages in more meaningful conversations, interactions many of which are free of the superficial subject matter that was common prior to this injury. He also feels he approaches communication differently as a result of the shift in his level of dependency. Although people approaching him sometimes are nervous about, and unsure of, how to conduct themselves, he is knowledgeable of the problem and takes a proactive approach.

I feel honored to be able to share Greg's experiences. As a mentor to me, he has been a wonderful resource as he is someone who knows what those who are going through the transitional process from able-bodied to disabled often are encountering. Although he feels he is no longer able to command the same attention as before injury, for me, his talent certainly was not lost to physical disability. In fact, in some ways, we could say he has won as a result of his injury.

Chapter 4: I've Changed. I Don't Mind

Conclusions

The insights gained from participants are invaluable to this study, because they present us with a definitive perspective on persons' negotiation of communication and identity in the aftermath of disability. More specifically, we learn ways identity is reestablished through the management of assistance, the management of relationship dynamics, and the use of humor and other conversational strategies—phenomena inseparable from communication. The ways participants describe their experiences with this phenomenon are essential, as it takes us directly into their lived experience. I use this final chapter to offer conclusions on communication, identity and disability, as reflected upon through the insight gained through the interviews.

This research was interested in looking at ways communication changes between those who have acquired physical disability and those they communicate with. The changes that are brought about by physical disability need to be communicated in order to navigate the change in identity to include new realities, another area of inquiry for this research. Lastly, factors that prevent disabled individuals from effectively conveying their needs and identity performances were also explored. For better organizational purposes, I'll revisit each of the research questions that have guided this project in reverse order.

The most apparent symbol complicating communication is physical limitation. The physical limitations are the catalyst for many of these changes yet it is often overlooked (all four of the participants fail to explicitly list "disabled" (or

any related identifier) as one of their identifying factors). Without the ability to function in the same exact way as everybody else normalcy, social interactions, and daily living must be adjusted.

Disability brings with it a reality that one who is disabled cannot function in the exact same way or level as one who is not disabled. As a result accommodations to navigating and surviving in the physical world must be made. This does not mean that the disabled life is inferior, it only means that various items will be more challenging for the disabled individual. These challenges create moments in which communicating a given identity will be complicated as a result of the disability. These complications alter the pre-injury identities conception of normalcy to accommodate the new realities that are presented to many disabled persons.

When normalcy is adjusted it can prompt communicative problems as definitions for various symbols can be altered. The new interpretations of what various items are (e.g. wheelchair=chair, adaptive biking=biking) can create miscommunication when participating in communication across different communities. The additional qualifying may be viewed as inferior by those who are ignorant to the disabled community.

Social interactions with people who are not familiar with disability can bring about a multitude of issues for newly disabled individuals. These persons run the risk of being patronized, not being understood or listened to, or fall victim to individuals avoiding you in unsuccessful attempts to not expose their ignorance. Each situation can hamper a disabled person's effort to be clearly understood and respected.

As we do not live in the perfect world that Sara mentioned, there are things that will limit disabled persons' ability to live unconstrained lives. The inability to participate in physical activities and the physical aspects of daily living confines the ability to connect socially through such performances. Each of the items stated prior create more challenges for those who are disabled and act as significant obstacles in the expression of a disabled individual's identity.

In overcoming these challenges, I have shown through this project how some disabled individuals participate in identity-shaping communication. The evidence documented has shown three factors most common throughout the data associated with the feat of establishing oneself with others: communicative acts that help to establish identity, acts that help to manage assistance, and the use of humor. I will describe each separately.

Mike's insistence on carrying his own books helps to establish much more than the fact he does not want assistance. Declining the offer shows his capability, which, in turn, helps to show he is a capable individual. On the other hand, Ryan's specific approach to recruiting helpers does this in the same way. By purposefully choosing specific individuals for assistance, he is able to manage the perceptions of others in a way that offers different performances depending on your relationship to him.

Sara's steadfast management of unwanted assistance keeps unwanted help away effectively. By demonstrating her ability to act independently she wards off any offers she may receive out of sympathy (again at a potential cost). The messages sent using these methods act to negotiate her identity proactively.

Greg's correcting of the parents who limit the questions their children have allows him to field questions and have a voice. The dialogue that follows allows him to set the record straight by providing answers that otherwise may have relied on faulty assumptions. By having the chance to educate people he is able to clear up misunderstandings about disability as well as his own identity. All of these examples display a specific way of allowing individuals with disabilities to express their abilities, their preferences, and ultimately their identity.

Next, certainly humor is very diverse. It can be used as a way to eradicate nervousness and begin building rapport, and as a way to reestablish one's membership in a group. Whatever the purpose, many people with disabilities have found humor, like other approaches, useful in cutting through many of the misconceptions and anxiety that others might bring to the communication environment.

Struggles in experiences like these point to just a few of the changes that are present in the disabled communication community. The changes documented in this study, I would propose, took place as result of many different reasons. Factors include: shifts in individuals with disabilities as a result of transitions to their disabled selves and gained perspective. The pressures of living the disabled life force the individuals with the disability to change. Another side is the shift that occurs in others as a result of their reactions to the initial disability, changes in relationship, and changes that still persist today. This shift in others, people who are in no way physically affected by the disability, creates a complicated situation riddled with confusion as they are adjusting their communicative responses simply

as a result of another's disability (i.e. they do not shift because of any personal struggles or forced changes in lifestyle.)

This project shows that, after becoming disabled, individuals can go through a transitional period where they must bid adieu to their former selves. A debilitating injury charges a person who suffered it with making sense of their new reality. Coming to terms with the finality and seriousness of the prognosis is not easy or instantaneous. The feeling has been characterized as "total shock," possible denial, and "a struggle to visualize happiness." The loss of one's social place, coupled with the humiliating personal care, can certainly take its toll.

As a result of growing as a person through the experience of overcoming our damaged identities each person is able to reflect a gained perspective of the world around them. They display these changes communicatively, for instance, in the ways they self identify, and via their everyday interactional styles.

Another side of the communicative change that takes place is a result of changes in the way that nondisabled acquaintances and strangers initiate and complete communication with their disabled counterpart. Initially, following the acquisition of the injury, friends and family altered their performances when in the presence of disability. The polite smiles instead of laughter, the act of putting on a strong face and accompanying hesitations, and the reported strengthening and deepening of relationships: all these factors characterize the communicative readjustment that takes place in defining questions along the lines of, what are my duties as a friend? How should I act? How can I help? And am I going to do something wrong?

The non-disabled others also make up a major change when in the presence of a disability. That change can come about through the offering of assistance which is something that still continues long after an acquaintance's injury. Examples of this, pertaining to how others communicate during exchanges of assistance, permeate every interview. Thankfully as a result of exposure, those who are familiar with the communication environment are less likely to act in a way that is not correct in the eyes of the disabled party as identity and expectations have been established. However, the issue that still persists with the helpful others who are not initiated into the specific preferences of the person with a disability. This causes the disabled individual to confront the challenges frequently when interacting with strangers.

Through these shared interactions symbols are created that are communicatively interwoven. Said symbols help to establish meaning and their presence acts to communicate context and information about the individual who is disabled. The interviews above, when viewed through this frame of symbolic interactionism, yield several symbols that are unique to the communicative environment.

The presence of humor acts as a symbol of normalcy. When used in combating the ambivalence of those who approach communication with the disabled with hesitation, humor helps express that it is ok to laugh and joke while in the presence of disability. Similarly, the act of performing physical tasks symbolizes the capabilities of the performer and helps to form perceptions of the person's self.

Going Forth

The purpose of this study was to explore the communication differences that accompany physical disability, how these changes are communicated, and what problems occurred through the process. My hope has been to bring increased perspective and knowledge of the disabled community to all who have taken the time to bear witness to the participants' experiences as well as my own. I hope this project has helped readers to become more knowledgeable in the presence of the obstacles prevalent to this phenomenon. Moreover, I hope readers employ the tips suggested by participants and avoid the pitfalls that have been experienced by others while participating in the disabled communication environment. Doing so will help create environments that foster clearer communication, provide more equal and unobstructed opportunities to establish identities, and offer disabled individuals chances to show how dynamic, interesting and normal they are, even with their disabilities.

Limitations of the study

Research, and especially qualitative inquiry, can be a fickle process. Although my aim has been to demonstrate thorough evaluation in the analysis and conclusions of the gathered data, all findings are nonetheless limited. I follow by describing some of those limitations.

Identity is never a static phenomenon; that is, it is always changing. Trying to isolate changes in identity to one specific moment or cause is not an easy thing to do. Many things in the lives of disabled persons could potentially alter their perspectives and interpretations of themselves. This difficulty is compounded by the

amount of time that has expired since each participant's injury. Simultaneously time could be an issue in the sense that not enough has elapsed for the respondents to more fully understand their own changes and the impact that their disability has in their life. Thus, the considerations of identity in this project are limited and certainly reliant on the fair and accurate recall provided by the respondents.

Also, the selection of participants provided results that are not representative of the disabled population as a whole. Greg alluded to this when he stated that he did not feel he was good respondent, because he has the financial means to support his disability, associated costs, and he has a strong social network of support. These are things that not every disabled person is fortunate enough to have. All four of my participants have health insurance and all reported having strong social connections. These two factors alleviate a large amount of stress that otherwise would compound the issues and difficulties associated with coming to grips with the profoundness of one's injury. Therefore, it is important to keep in mind that a large section of the disabled community is unable to report such successful rehabilitation. Each participant is able to participate in his or her community at various levels. Some who are disabled do not have the means to leave their homes let alone their beds. Lastly, the psychological burden and relational strain of bankruptcy caused as a result of paying hospital bills is not reflected within this study.

Disability is a very large umbrella term, as is physical disability, as is spinal cord injury. Each participant's interpretation of the roles that others need to plan in terms of assistance can be heavily determined on their severity of injury. Greg's love

for all of those who are offering to help could be explained as a result of his inability to command much of his physical environment. Sara on the other hand is more capable of navigating her surroundings and being completely independent. She might find the offers for assistance extremely annoying as she does not feel she needs it. Thus, I am very cognizant of the significant impact injury level and severity can have on affecting the individual's approach to their communication following disability and their disabled identities.

The interview structure is also vulnerable to inaccuracies. When allowing the participants to self identify, they are able to perform in whatever way they please. This opens the door for the possibility of exaggerating or minimizing certain personality traits, to give a specific altered characterization of themselves. Thus, I may not have gotten an absolute accurate account of each respondent's experiences as it was not fact checked or corroborated by others who laid witness to the experiences.

Lastly, in this study, I did not dig too deep into the effects of other demographic information besides that of requiring participants to be an individual with a disability. Much research has been done on the effects of age, race, class, sex, sexual orientation, etc. and its effect on identity management. To assume that identity alone can supersede all these other forces is narrow minded. An example of how sex could affect door performances could be the presence of chivalry and how those who are disabled and female receive more assistance than those who are disabled and male.

Areas for Future Research

To be sure, disability is not something that is easily isolated. Future areas of inquiry can continue my effort to focus on specific types of injury and their associated impact on identity. For instance, it would be interesting to more closely examine the similarities between how those with spinal cord injury resolve their differences when compared to others who have acquired forced change (serious illness, broken bones, divorce).

Most communication-related research is made difficult by the multifaceted nature of the discipline. It makes it very difficult to ascertain that a given factor is really the cause of a given phenomenon. By continuing to address issues like those proposed, the web of knowledge can be expanded to connect similarities between moments that seem otherwise unrelated. Having more insight available about similar topics results in a more holistic understanding of the themes and factors of the research.

Future projects can take the work I have started one step further by focusing even more closely on the identity of disabled individuals. I think two specific projects could build on what I have started: an exploration of identity management of those who are completely paralyzed and a look at how those with acquired disability (similar to the participants of the study) manage their disabled identities differently from those born with disabilities.

As evidenced by the Greg interview a complete loss of independence is much more profound than that of partial paralysis. Although those who are paraplegics only lose portions of their physical ability the complete forfeiture of movement

creates added challenges in being able to be a successful communicator within our incredibly physical world. Along with that potential research thread, the compare and contrast between acquired and biological disability pertaining to identity management and communication patterns will provide an interesting look at the differences between the two. I'm curious to know if there are additional challenges and having to rectify an already established identity or if trying to make sense of a lifelong disability produces similar challenges.

No Longer the Same?

The inspiration for pursuing this project came when a fellow graduate student, following a class session in which I disclosed my disability, said to me, "let me get that for you" as she stepped in front of me to open the door. On my commute home I realized the potential of addressing the differences that occur once disability is present. Although her actions acted as a catalyst for this project, several distinctive moments from my time spent as an individual with a disability contributed to the same call for academic exploration into the phenomena.

Now looking back, performing this research was incredibly enlightening in many different ways. I was able to explore myself and my own management of my disabled identity. I was also fortunate enough to be able to hear the experiences of four other individuals who have underwent the transition.

Consequently, I learned new perspectives that challenged my own handling of various situations. Although I posit myself as knowledgeable of the disabled community, I discovered several facts and perspectives that enhanced my understanding of the community. I came to realize that there are several ways, and

not just a few, to accomplish the same goal each with its pros and cons. The diversity of opinion amongst the respondents provided four different answers that, indeed, all were correct. Also, I have definitely expanded my understanding of the disabled community, yet, still remain unsure about how I might handle specific examples similar to Sara's tumble. Hopefully I can take solace in the advice that I have heard several times to just stay calm and respectful.

Through the process of interviewing others, I came to learn more about how I would possibly respond to the various situations that were described by the respondents in the interview questions. The varying perspectives of how to manage and accept assistance provided me with a diverse way to approach the issues I encounter myself. For example, the times I try to navigate the nervousness that still persists among distant friends, acquaintances, and strangers who are knowledgeable of my disability. Opening cans and packaged items still provide me with a challenge that makes me wonder how long I should attempt entry before awkwardly asking for assistance. Being able to talk with those who face similar little problems like that on a daily basis has provided me comfort that I'm not alone and that my minor struggles are certainly normal, all things considered. Hopefully I was able to provide the same support to them.

I came to realize that the line between researcher and friend can get quite fine. During the write-up process I have questioned the inclusion of potentially sensitive pieces of data. I feel I have retained my intention to remain honest to my participants, as well as my commitments as a researcher. When reflecting on the dilemma, I enjoy Ellis' (2007) bluntness in the discretion the researcher has: "In life,

we often have to make choices in difficult, ambiguous, and uncertain circumstances. At these times, we feel the tug of obligation and responsibility. That's what we end up writing about" (p.26). I believe that reframing the obligation and responsibility as researchers to accurately represent and capture the scene is a great way to emphasize the true goals that researchers should have for themselves. I left some responses on the cutting room floor, but believe that those making it into the document genuinely capture the essence of participants' insights.

Indeed, this project is just one path on our trek to better understand communication and identities by/among/with disabled communicators. I do hope that what I have presented sheds light on the complications that are present, some methods that are employed to help ease these complications, and the differences in identity that are created as result of the acquisition of a physical disability.

I am not the same person I once was. Who I am today is a result of my ability and inability to impress certain attributes about myself on others. Although I have been negotiating communication and identities my entire life, the last six years have been marked by moments of complete embarrassment and extreme confidence. As a disabled individual I have faced challenges I otherwise would not have faced in establishing my identity with others. Through trial and error I have emerged proud to be who I am, a person adapting to life with a disability. As I continue to make sense of my circumstances, Act II of my life is coming to a close. I readily await the next Act. Granted, disability will always be a profound component of my identity. Still, I soon hope to outshine its presence with other important identifiers, such as: Husband, Father, Mentor, and Leader. Because, as evidenced by the participants,

although one may be disabled it cannot limit his or her vivacity to accomplish goals and live life to the fullest.

References

- Alcoff, L. (1991). The problem of speaking for others. *Cultural Critique* , 20, 5-32.
- Braithwaite, D. O., & Eckstein, N. J. (2003). How people with disabilities communicatively manage assistance: Helping as instrumental social support. *Journal of Applied Communication Research* , 31 (1), 1-26.
- Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry* , 13 (3), 3-29.
- Goddard, S., & Torres, M. B. (2009). Conflict, face, and disability: An exploratory study of the experiences of college students with disabilities. *Paper presented at the annual meeting of the International Communication Association, Marriott, Chicago, IL* , 1-25.
- Goffman, E. (1959). *The presentation of self in everyday life*. Garden City, NY: Doubleday.
- Hart, R. D., & Williams, D. E. (1995). Able-bodied instructors and students with physical disabilities: A relationship handicapped by communication. *Communication Education* , 44, 140-154.
- Kuhn, T. S. (1970). *The Structure of Scientific Revolutions* (2nd ed.). Chicago: University of Chicago Press.
- Leeds-Hurwitz, W. (1995). *Social Approaches to Communication*. New York: Guilford Press.
- Lindemann, K. (2008). Cleaning Up My (Father's) Mess: Narrative containments of 'leaky' masculinities. *National Communication Association* (pp. 1-29). San Diego: National Communication Association.

Lindlof, T., & Taylor, B. (2002). *Qualitative Communication Research Methods* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Park, J. H., Faulkner, J., & Schaller, M. (2003). Evolved disease-avoidance processes and contemporary anti-social behavior: Prejudicial attitude and avoidance of people with physical disabilities. *Journal of Nonverbal Behavior*, 27 (2), 65-87.

Reeve Foundation. (2010, May). *Paralysis Facts & Figures*. Retrieved May 7, 2010, from Christopher & Dana Reeve Foundation:
http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.5184189/k.5587/Paralysis_Facts_Figures.htm

Appendix I

The University of Wisconsin-Superior

Communicating Arts Department

Consent Form

This project is being conducted by Luke Green. He is a graduate student from the University of Wisconsin-Superior conducting research under the advisement of Keith Berry, Ph.D.

You are invited to participate in a research study exploring identity management following the acquisition of physical disability. You have been asked to participate because you fit within the desired parameters of the study. The purpose of the research is to explore what identity shifts (if any) occur following the acquisition of a physical disability. This study will include adult males who have had a physical disability for at least three years. The research will be conducted via interviews between the researcher and participants. Participants will benefit from being a part of the study by being able to help inform others about what a physical disability is and is not. Information provided will help to dispel any misunderstandings that the public has about those with disabilities. Participants should be comfortable speaking of their experiences. Participation is not recommended for those who when discussing their disability have feelings of anxiety, depression, or any other issues as participation may provoke these feelings.

Your participation is completely voluntary. If you decide to participate in this research you will be asked to complete a demographic questionnaire, a Twenty Statements Test, and up to two 20-30 minute interviews.

Your participation will consist of approximately one hour of time.

Participants will be asked various questions pertaining to their personal disability and social interactions with those close to them as well as strangers. Participants will have knowledge of the questions prior to the interview itself. Afterwards participants will be informed of how to receive a copy of the final project if interested.

If at any time during this study participants may choose not to answer any questions they do not want to and may leave the study at any time for any reason. All personal information gathered will remain confidential and any identifying information included within the report will be protected through pseudonyms and editing.

You may ask any questions about the research at any time. If you have questions about the research you should contact Luke Green by e-mail at Lgreen1@uwsuper.edu.

If you are not satisfied with response of the research team, have more questions, or want to talk with someone about your rights as a research participant, you should contact Keith Berry or the Institutional Review Board at the University of Wisconsin-Superior.

Jim Miller, IRB Coordinator
Telephone: (715) 394-8396
Email: *JMILLER@uwsuper.edu*

This research project has been approved by the UW-Superior Institutional Review Board for the Protection of Human Subjects, protocol #640

Your signature indicates that you have read this consent form, had an opportunity to ask any questions about your participation in this research and voluntarily consent to participate.

Name

Signature

Date

Appendix II
Demographic Information

Age:

Sex:

Date of Injury:

Type of Injury:

Twenty Statements Test

There are 20 numbered blanks on the page below. In the blanks provided, please fill in up to 20 brief answers to the given questions concerning your perceived identity : Who were you? and Who are you? as a result of your disability. Please give up to 20 different answers to each of these questions. You are not required to fill all 20. Write your answers in the order that they occur to you. Do not worry about logic or 'importance' any response is acceptable. Please complete as quickly as possible.

Prior to acquiring your physical disability, who were you?

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.
- 11.
- 12.
- 13.
- 14.
- 15.
- 16.
- 17.
- 18.
- 19.
- 20.

(Please take a break for a few minutes before continuing to the next page)

Today, who are you?

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.
- 11.
- 12.
- 13.
- 14.
- 15.
- 16.
- 17.
- 18.
- 19.
- 20.

(Twenty Statements Test adapted from Kuhn, M.H. and McPartland, T.S. 1954)

Twenty Statements Tests

These are the unedited responses given by the participants for both of their TSTs. Any blank spaces represents where the respondent did not indicate additional identifying features. Below the last pair of tests is a brief analysis of some common themes found among the responses.

RYAN

Prior to acquiring your physical disability, who were you?

1. Loving Person
2. A friendly guy who loved meeting people
3. Loves to Party
4. Outgoing person
5. Loves his space and isolation sometimes
6. Going to concerts (not anymore)
7. Super attractive guy
8. Athletic
9. Slightly Religious (me and Jesus were always tight)
10. Cool guy, loved hanging with bros
11. A fan of snow (I'm not anymore)
12. Lazy Person
13. Loved traveling
14. A rebel (against parents in some ways)
15. Semi politically conservative person
16. Could be very selfish
17. Determined to do everything
18. Loved to learn
19. Nervous and sweaty in some public speaking and similar situations
20. Leader, always loved to help

Today, who are you?

1. Still loves
2. Loving person, hopeless Romantic
3. Still loves to party
4. Still outgoing but not as much
5. Likes his time and space
6. Knows truly how people love him, due to all the sympathy he got
7. Has no decency anymore due to my time in the hospital,
8. Still attractive
9. Greater perspective on medicine and for disabled people

10. Funny guy, love jokes
11. Adjusting to life in chair
12. Always determined
13. Never try to think what life would have been
14. No more nerves or stuttering in big crowd, speech, nervous moments.
15. New love for family
16. Still loves god no real change in faith at all
17. Political views have changed to more liberal ideas in some areas
18. More thankful and grateful person, because of everyone who has helped me
19. More intrigued in education and learning
20. More pain, my butt hurts a lot

MIKE

Prior to acquiring your physical disability, who were you?

1. Soccer Player
2. Skier
3. Mountain Biker
4. Paint-Baller
5. Student
6. Server
7. Socialite
8. Backpacker
9. Camper/boundary waters
10. Faith driven
11. Wacky dancer
12. Hunter
13. Pretty Care free
- 14.
- 15.
- 16.
- 17.
- 18.
- 19.
- 20.

Today, who are you?

1. Road Biker (handcyclers)
2. Kayaker
3. Camper (Havent made it to the boundary waters quite yet)
4. Student
5. Guitar Player
6. Problem Solver

7. Social (not quite as much as I used to but I'm working on it ☺)
8. Sales Man (should hopefully be at best buy this summer)
9. Volunteerer
10. Faith Driven
11. Still a wacky dancer
12. Hunter (still working out the finer points)
13. Still filled with some grief (we all have our days..)
14. Slightly more cautious/ realistic
- 15.
- 16.
- 17.
- 18.
- 19.
- 20.

SARA

Prior to acquiring your physical disability, who were you?

1. I was a runner
2. I was outgoing
3. I was a college student
4. I was single
5. I was a counselor for high risk teen girls
6. I was fun to be around
7. I was a night owl
8. I was training to run Grandma's Marathon or Half Marathon
9. I was a fan of outdoor activities
10. I was a regular patron at a local pool hall
11. I was happy with life
12. I was looking forward to the future
- 13.
- 14.
- 15.
- 16.
- 17.
- 18.
- 19.
- 20.

Today, who are you?

1. I am a wife
2. I am a mother
3. I am a graduate student
4. I am outgoing

5. I am passionate
6. I am an advocate
7. I am determined
8. I am independent
9. I am happy
10. I am creative
11. I am proud
12. I am blunt
13. I am inspired
- 14.
- 15.
- 16.
- 17.
- 18.
- 19.
- 20.

GREG

Prior to acquiring your physical disability, who were you?

1. I was tall, physical, no glasses and blonde.
2. I was a respected businessman with a career on the rise.
3. I was fun and spontaneous.
4. I enjoyed family and friends.
5. I was good at all sports.
6. I commanded attention.
7. I was honest and had integrity.
8. I worked hard and played hard.
- 9.
- 10.
- 11.
- 12.
- 13.
- 14.
- 15.
- 16.
- 17.
- 18.
- 19.
- 20.

Today, who are you?

1. I am short (relatively) because I sit.
2. I am seen as heroic for dealing with when I have dealt with.
3. I enjoy family and friends.

4. I am a parent.
5. I draw attention.
6. Most of me is the same guy, but the physical aspect of me is gone.
7. I am honest and have integrity.
8. I can't work as hard.
- 9.
- 10.
- 11.
- 12.
- 13.
- 14.
- 15.
- 16.
- 17.
- 18.
- 19.

Appendix III

Each interview will be shaped largely by the respondent's unique experience and their recollection of it. For the purpose of maintaining consistency among all of the interviews a core group of themes will be touched upon within each interview.

These themes include:

1. How would you describe yourself prior to your injury?
 - a. What were your identity roles?
2. What was your initial reaction to your injury/learning your prognosis?
 - a. How did you react to others and vice versa?
3. Did you notice any relational changes during your rehabilitation?
 - a. How were you able to manage them?
4. How did your friends, family, acquaintances adjust after acquiring your disability?
 - a. Were there any obstacles that prevented you from communicating effectively?
 - b. How were they overcome?
5. What do those who are able-bodied and disabled not understand about your identity?
 - a. How do you express your needs through communication?
6. What do you wish those who are able-bodied understood about you and your disability?
 - a. How have you tried to communicate these understandings to others?

7. What if anything do you love about being an individual with a disability?
8. What makes you unique from others with physical disabilities?
9. How do you manage assistance that is needed and unneeded?

Are you still the same person you were prior to your injury or have you changed?