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ROLLING MANHOOD: HOW BLACK AND WHITE MEN

EXPERIENCE DISABILITY

by

ALEXIS A. BENDER

Under the Direction of Charles Gallagher

ABSTRACT

Sociologists have only recently paid attention to how men experience physical disability. However, current research continues to ignore how different racial groups experience it. The goal of this study was to examine how black and white men experience life with a physical disability. Using qualitative research techniques involving in-depth, face-to-face interviews with 10 black and 10 white men, I focus on how meanings of disability and masculinity shift after a traumatic injury. Using symbolic interactionism and social construction as theoretical frameworks, I examine how these men formed and modified meanings for disability and masculinity through social interactions. I also analyze the strategies they use to manage a stigmatized identity. Finally, I explore how they negotiate a masculine identity within larger social contexts. My findings suggest that black and white men's constructions of masculinity and disability are more similar than different on all levels. Furthermore, these men used three strategies to negotiate their new

social identities: reinforcing idealized masculinity, modified masculinity, and lost masculinity.

INDEX WORDS: Disability, Masculinity, Spinal Cord Injury, Stereotypes, Perceptions, Race

ROLLING MANHOOD: HOW BLACK AND WHITE MEN EXPERIENCE DISABILITY

by

ALEXIS A. BENDER

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

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2006

ROLLING MANHOOD: HOW BLACK AND WHITE MEN EXPERIENCE DISABILITY

by

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CHAPTER I: INTRODUCTION

Spinal cord injury (SCI) and other disabilities affect all facets of life, not just physical functioning. A traumatic SCI not only causes obvious muscle paralysis, it can also affect bodily functions such as sensation, respiration, bowel and bladder control, temperature regulation, and sexual function. SCI affects a person's physical, social, vocational, and psychological functioning (Rohe and Krause 1999). The National Spinal Cord Injury Statistical Center (NSCISC) estimates that 11,000 people sustain a spinal cord injury from trauma or disease annually in the United States and that approximately 250,000 people live with SCI (2006).

This project began after my partner experienced a catastrophic injury resulting in a SCI. Three months after his injury, his employer terminated him because they did not foresee the possibility of his return to work. He found himself suddenly facing life with paralysis from the neck down, and having lost the defining element of his life prior to his injury: his work. He, like many other American men, tied his self-worth to his occupation. With the loss of his job, he did not feel he had a reason to get better. This experience replaced his identity as a professional employee with an identity of a quadriplegic.

The pressure of losing his job and facing significant impairment caused him to become withdrawn and start to cry. A nurse, witnessing this, encouraged him to cry, although this expression of emotion discomforted him. Other female nurses also gave

him permission to cry. The act of crying goes against the strong, stoic ideal presentation that is expected of men by themselves and others. Within this social institution, he was encouraged to go against all he had been taught about controlling his emotions. The nurses who gave him permission to cry were also giving him permission to let go of a traditional version of masculinity.

The nurse made a statement that caused me to take notice. She said, “It is amazing to me. I have worked here for ten years, and in that time I have seen almost every white man cry, but I have never seen a black man cry. I don’t know why that is.” As a result, I became interested in how men experience sudden shifts within their social worlds as the result of traumatic injury. Particularly, what are the differences in how white men and black men experience these shifts? I thought there might be an extensive body of literature detailing the racial differences in the grieving process among men with sudden physical disabilities, or at least about the experiences of men with acquired disability. However, I could not find any research comparing the experiences of different racial groups and very little about men in general in regards to disability. This glaring gap in existing literature became the starting point for this study.

Beyond the lack of information about the experiences of these groups, I focus on black and white men for two main reasons. First, the physical changes associated with disability are at odds with the stereotypical notions of masculinity including strength and virility, which will create experiences unique to men (Lorber and Moore 2002). Second,

black[1] men have historically been denied the opportunity to fill the role of hegemonic "man" through systematic oppression and marginalization. The aim of this study is to develop an understanding of the experiences of disability among men and to explore the differences and similarities among black and white men. I approached this by interviewing 20 men who have an acquired physical disability, specifically SCI, and in one case, double amputation. I focused on men who sustained an injury after the age of 18. I explore their views of life with a disability, including themes of work, dating, intimacy, sex, friendships, and family. During this project, I focused on the ways these men construct their masculine identities in relation to their understanding of disability. I found more similarities than differences between black and white men's construction of masculinity. Because of this, I only offer an analysis of race in the areas that I found differences. This thesis begins with a review of the existing literature on the causes and outcomes for people with SCI. The literature review continues with a discussion of the major themes in masculinity research. Then, I examine the existing literature on disability. In this section, I identify where researchers have examined the intersections of masculinity or race in their analysis as a background for understanding what other researchers have found, and where gaps still exist in the literature. The following chapters include the methodology I employed, three findings chapters and a conclusion. In the discussion of my methodology, I explain my qualitative data collection and analysis

[1] I focus on black men in this study; however, there are points in the existing literature that do not specify "black" when referring to "minority." At points that I use the term minority, I am using the language of the authors if they have generalized to include other racial minorities.

procedures. I also discuss the theoretical frameworks I used in this study. I used symbolic interactionism and social construction theory as a basis for understanding these men's lives.

I present my research findings in the three subsequent chapters. In the first of the three, I discuss how respondents interpret the meanings of disability. I examine how respondents make sense of their changing self through symbols and interactions both before and after their injury. This chapter serves as a background for understanding disability in these men's lives. In Chapter Five, I explore how these men actively construct and modify their meanings of masculinity. In this analysis, I examine the tactics these men use to construct a new reality aimed at meeting the hegemonic norms of masculinity and ways they resist the expectations to conform to hegemonic masculinity. Chapter Six is an analysis of the social ways that these men are denied access to typical expressions of masculinity, like independence and employment. The final chapter in this thesis offers suggestions for future research.

CHAPTER II: REVIEW OF THE LITERATURE

Spinal Cord Injury

In order to fully understand the ways in which the men in this study formulate notions of masculinity in response to SCI and similar impairments, it is important to understand the physical, economic, and social outcomes for people with SCI. SCI often results in severe disability that affects every facet of a person's life. Despite improvements in medical technology that allow most people with SCI to live a near-normal life span, other areas of their life are still greatly impacted by their injury or by disease. The following data show that the rates and etiology of SCI vary by gender and race and the intersections of these factors affect the outcomes experienced by all groups. Furthermore, men of all races are more likely than women of all races to experience SCI, and whites are less likely to be victims of violence and more likely to have social support and economic independence than blacks. These statistics highlight the need to examine how these differences shape the experiences of catastrophic injury for white men and black men. This section will address the injury rates and causes of SCI followed by a discussion of how SCI affects employment rates, relationships, community involvement, and psychological well-being. I present data that are available about racial and gender differences on all levels.

Causes of SCI

SCI can occur because of trauma or disease; since 2000, 47.5 percent of all SCIs were the result of automobile accidents. Less common causes of spinal cord injuries were falls (22.9 percent), violence (13.8 percent), sports (8.9 percent), and other/unknown causes[2] (6.8 percent)[3]. Within each of these categories, there is no further breakdown of specific causes. For example, we cannot determine if an injury categorized as violence is the result of a gunshot or stabbing, or if the violent act was intentional, accidental, or in the line of duty as a member of the police or military.

In addition to the causes of SCI, the SCI database notes a few trends over the past five years that are directly relevant to this study. Currently, 79.6 percent of the reported spinal cord injuries occur among men. This percentage is down slightly from 1980, when men reported 81.8% of the new cases. These injury rates show that SCI disproportionately affects men. According to the 2000 Census, men accounted for 49.1 percent of the U.S. population. The average age at the time of injury is 37.6 years. Most people injured between 1973 and 1979 were white (76.8 percent) followed by 14.2 percent black, 6 percent Hispanic, and 3 percent from other racial/ethnic groups. This distribution does not differ drastically from the 1980 Census, which reports the racial distribution as follows: 83.1 percent white; 11.7 percent black; and 6.4 percent Hispanic

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[2] This category includes disease and infection.
[3] Unless otherwise noted, all statistics reported regarding SCI were drawn from the National SCI Database. www.spinalcord.uab.edu

(Campbell and Jung 2002). Since 2000, however, they note that rates for whites (62.9 percent) and blacks (22 percent) have decreased but have increased among Hispanics. The more recent injury rates show a disproportionate level of SCI affecting minority communities. According to the 2000 U.S. Census, whites account for 75.1 percent of the population and blacks account for 12.3 percent (2000).

Violence

Gordon and Lewis (1993) argue that young inner-city black males disproportionately represent the growing number of spinal cord injuries. The NSCISC concludes that it is unknown whether the change in location for spinal cord rehabilitation centers, the referral patterns to model spinal injury centers, or race-specific incident rates account for the trend in injury rates. Other researchers (Anderson, Dyson, and Grandison 1998; Anderson, Grandison, and Dyson 1996; Go, DeVivo, and Richards 1995) state that violence, accidental or intentional, (gunshots, stabbing, and other violent causes) is the primary cause of SCI among blacks. Research by Nobunaga, Go, and Karunas (1999) support these findings by noting that violence-related injuries increased dramatically from 13.9 percent in 1973-1977 to 21.8 percent in 1994-1998 (1999:1372). When examining causes of injury by race, Nobunga, Go, and Karunas (1999) highlight that violence accounts for 46 percent of injuries for all blacks while only accounting for 7 percent for whites. It is difficult to determine how individuals who experience SCI

because of violence relate to the act of violence, whether as a member and participant in gang activity or as a bystander in urban violence, to list two possibilities.

Employment

Finding and maintaining employment is one of the greatest challenges faced by people with SCI. According to the Employment and Disability Institute at Cornell University, people with spinal cord injuries fare worse than those without a disability on social, economic, and psychological outcomes and fare about the same as people with other forms of disability, such as Multiple Sclerosis, Cerebral Palsy, and Traumatic Brain Injury (Disability Status Reports 2005). Although more than half (64.1 percent) of all people with a SCI were employed at the time of injury, after 10 years, 32.8 percent of people with paraplegia and 24.7 percent of those with tetraplegia[4] were employed (NSCISC 2006). Employment provides more than financial benefits; it also has social, political, and psychological implications (Meade, Lewis, Jackson, and Hess 2004). People with SCI list multiple reasons for not working, including: physical inability to perform the same kind of work they did prior to their injury; poor health, stamina or

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[4] **Tetraplegia (also known as Quadriplegia):** refers to SCI above the first thoracic vertebra. Paralysis affects the cervical spinal nerves, which results in paralysis of all four limbs. In most cases, paralysis is present in the arms and legs. Additionally, the abdominal and chest muscles are also affected, which will result in weakened breathing and the inability to properly cough and clear the chest. Quadriplegia is the more commonly heard term referring to this level of injury. Medical practitioners and more people who are recently injured use the term Tetraplegia to include a fifth location of paralysis (the trunk). **Paraplegia:** is when the level of injury occurs below the first thoracic spinal nerve. The degree at which the person is paralyzed can vary from the impairment of leg movement, to complete paralysis of the legs and abdomen up to the nipple line. Paraplegics have full use of their arms and hands.

endurance; loss of health benefits; not feeling physically capable; inaccessible workplaces; and lack of transportation (Targett, Wehman, McKinley, and Young 2004).

There are differences by race in employment rates before and following SCI (Meade et al. 2004) and these disparities reflect patterns in the general population. Distinct differences exist between blacks and whites with regard to employment at the time of injury. According to Meade et al. (2004), blacks had lower employment rates compared with whites (50 percent and 73 percent respectively) and higher rates of unemployment (37 percent and 11 percent respectively). Blacks who were working were more likely to have lower-paying positions (labor and service workers) than whites (2004:1790). The disparities seen at the time of SCI are only complicated by the experience of SCI. Following injury, research indicates that whites are more likely to hold employment than blacks (Hess, Ripley, McKinley, and Tewsbury 2000; James, DeVivo, and Richards 1993; Krause and Anson 1997; Young 1994). Krause et al. (1998) note that even when controlling for education, whites with SCI are 2.8 times more likely to be working than minorities with SCI. Furthermore, employment rates and student status for whites appear to increase over time while the rates stay constant for blacks. The gap in student status suggests a decrease in future potential for employment for blacks (Meade et al. 2004). Other economic factors, such as yearly health care and living expenses for those with a SCI (ranging from $14,670 to $127,227 based on level of function) can further limit employment opportunities.

Social Interactions

Beyond the economic impacts of SCI, social relationships are also affected. Among those who were married at the time of injury, as well as those who marry after their injury, the rate of divorce is slightly higher than the uninjured population. Additionally, it is less likely that one will marry after sustaining a SCI (National Spinal Cord Injury Statistical Center 2006). According to Stover, Richards, and DeVivo (1994) young blacks with spinal cord injuries are more likely than their white counterparts to be single or separated at the time of injury. Consequently, blacks lack some levels of family support to aid them as they adjust to life with a SCI.

Another aspect of social interaction is the amount of involvement one has with their community. When examining community integration as an aspect of well-being, research has found that whites were "more physically independent as measured by hours of assistance required, had better access to their community, and were involved in more productive activities than minority groups" (Krause and Broderick 2004). Those with SCI have less of a social support network than those who do not have an injury, and blacks are even further disadvantaged when SCI is a factor.

Psychological Well-Being

On the individual level, depressive disorders are the most common form of psychological stress for people with SCI and appear to be more common than in the non-SCI population (Krause, Kemp, and Coker 2000). Depression can affect multiple areas of

a person's life ranging from health, activities of daily living, and relationships. There is great variation in rates (15 percent to 35 percent) of depression depending on the time of measurement in relation to injury; however, regardless of time, the rates are always substantially higher than in the non-disabled population (Krause, Kemp, and Coker 2000).

Recent studies have noted important differences between whites and blacks with SCI in subjective well-being and depressive symptoms. Krause, Kemp and Coker (2000) report that minority SCI participants reported higher depression scores than white participants and Krause and Broderick (2004) found significant racial differences in subjective well-being. Krause and Broderick state that the largest differences in subjective well-being existed in areas "consistent with societal opportunities for full participation among people of all different races" (2004:360). These inequalities, based on Krause and Broderick's findings, appear in relation to socially competitive aspects of life, such as employment. Specifically, they found that whites report higher levels of subjective well-being in relation to finances and employment. Krause and Broderick (2004) also found that there were only small differences between blacks and whites in relation to engagement, negative effect, or health. These findings imply high levels of resilience among minority participants even when faced with fewer opportunities. These statistics and empirical studies indicate that SCI both dramatically alters the physical aspect of the body and has real implications for a person's social and economic future.

Gender

Examining the statistical information about SCI provides us with an understanding of some of the differences that exist between men and women relating to SCI rates and outcome. In this section of the literature review, I will examine the relative literature about the social construction of gender and the resulting inequalities. It is within social structures that people construct themselves as men or women, and thereby construct their gender identity. Gender operates within a hierarchical system with men viewed as more powerful and dominant and women viewed as less powerful and inferior. These power relations produce stereotypes of masculinity and femininity, traits and behavior that we expect of men and women (Connell 2002).

When examining the social construction of gender, Judith Butler (1990) states that gender is something we perform. Based on her theory of performance, from the moment gender is named – "it's a boy" – a person is put into a regulatory frame. Within this frame, the person (a boy in this case) would perform masculine acts, or they are performed for him at a young age. Although gender identity is complex and fluid, the displays of masculinity by the media, popular culture, and other arenas of social life correspond to the regulatory frame. This frame takes all the possible gender performances and practices and places them into a constricting bifurcated system of masculine and feminine (O'Neill and Hird 2001). Individuals are considered masculine when they portray themselves as strong, self reliant, successful, active, independent, tough,

aggressive, dominant, and stoic. They must also display sexual interest and prowess, not act like a woman, and should never cry (Bem 1974; Herek 1986; Tepper 1999; Zilbergeld 1992). The social construction of gender is achieved by "doing gender" within a situated context (Fine and Asche 1988; West and Zimmerman 1987). This means gender is not something that is natural or essential; rather the meaning of gender shifts based on the social context where the individual is situated. A more in-depth discussion of West and Zimmerman's (1987) concept of doing gender is included in my theoretical framework at the end of this chapter.

Masculinity

Within the area of gender studies, the study of masculinity or men as gendered individuals is relatively recent (Connell 2002; Morgan 1981). The first wave of men's studies, feminist studies of masculinity, had three defining features. First, as the women's movement was gaining momentum in the 1970's, men began writing about how boys were socialized to be tough and competitive and how men had trouble expressing their emotions (Coltrane 1994; Goldberg 1976; Kimmel and Messner 2004). Second, according to (Kimmel and Messner 2004), this first generation of research on masculinity was extremely valuable because it challenged the unexamined ideology that made masculinity the gender norm against which both men and women were measured. The third feature of the first wave of masculinity studies was the need for the scholars (white middle-class men) to look "outside" themselves in order to deconstruct "the naturalness

of white male identity" (Ross 1998:607-608). By stepping outside themselves, they began to see the ways white masculinity is privileged.

It was during this first phase of research on men that Connell theorized "hegemonic masculinity." According to Connell, hegemonic masculinity is "the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women" (1995:77). In other words, hegemonic masculinity provides a strategy for the domination of women (Donaldson 1993). Hegemonic masculinity is grounded in the behaviors and practices of white males, yet not all men achieve it. Marginalized groups are constantly constructing masculinities that vary from this hegemonic masculinity because they are denied access to "true" hegemonic masculinity (Dade and Sloan 2000; Harris, Torres, and Allender 1994). Even though hegemonic masculinity is exclusionary and many men never succeed in it, most men benefit from the idea of it (Donaldson 1993). Hegemonic masculinity does cut across class lines, but usually excludes working-class and black men. It is an idealized form of masculinity that perpetuates the stereotypical ideas of manhood, yet men benefit from it by their domination of women at a collective level.

A second phase of research on men and masculinities emerged in the early 1990's and addressed the exclusionary nature of hegemonic masculinity. Research during this time examined how variations among men are central to understanding men's lives

(Kimmel and Messner 2004). This stage of research problematized earlier studies that presented one version of masculinity - white, middle-age, middle-class, and heterosexual – as the norm by which all men were measured. Men who fit the hegemonic norm labeled those who did not as enacting “problematic” or “deviant” versions of masculinity (Kimmel and Messner 2004; Ross 1998). It is not only that middle-class, middle-aged, heterosexual white male masculinity was the standard against which all men were measured, but that this definition itself was used against those who did not fit as a way to keep them in subordinate positions.

The meanings of masculinity vary within any one society by the various types of cultural groups that exist within it. We cannot speak of masculinity in the United States as if it were a single, easily identifiable commodity (Kimmel and Messner 2004). To do so assumes one version of masculinity is the normative definition, thereby making all other masculinities problematic. The construction of masculinity differs by class culture, race, ethnicity, religion, sexual identity, age, etc. (Collinson and Hearn 2001; Kimmel and Messner 2004). Black constructions of masculinity may differ from white constructions of masculinity, yet class and age also further modify each of them. For example, black men have adopted cultural spaces, like the sporting arena, in order to define themselves and their masculinities (May 2004). While white men also use the sporting arena as a location to define and display their masculinity, sports are a focus for black men because it provides them with a context for expressing their male dominance.

This is different, because unlike white men, they have been prohibited from participating in other social, political, and economic activities due to overt racism and discrimination (Edwards 1982; Spraggins 1999). The Men, Masculinities and Socialism Group, an autonomous policy group of the Socialist Movement, expressed that masculinity is not something that is present in a single, uniform, and innate form. Rather, there are varieties of masculine forms and relations, which are often complex and contradictory, in the specific histories of "black, gay, bisexual, class-related, disabled, able-bodied, young and old, regional masculinities" (1990:18). Every form of masculinity has its own history and is manifest based on these histories.

One constant aspect of masculinity is that men's bodies have always been an issue within the study of masculinity, at least in terms of concepts such as strength, potency, and physical activity (Connell 1995; Morris 1991; Shakespeare 1999a). Morris (1991:93) argues "[hegemonic masculinity] is inextricably bound with a celebration of strength, of perfect bodies… It is also linked to a celebration of youth and of taking bodily functions for granted" (p 93). Perfection, in this sense, does not include vulnerability and weakness. Sport and bodily force provide indications of how a male body ought to look and function (Connell 1995). Connell argues that men are expected to present active potential. He says "what it means to be masculine is, quite literally, to embody force, to embody competence… Force and competence are, obviously enough, translations in the language of the body of the social relations which define men as holders of power, women as

subordinate" (1995:27). In other words, the masculine performance of gender centers on the body and that these arrangements are linked to power relations. Masculinity sets up boundaries for the performer to be active and physical. Masculinity takes away the option for men to be weak, vulnerable, imperfect, or old.

Another way that men's bodily performance as gender performance links to power relations is by measuring themselves against other men (Newton 1998). Connell states "to be an adult male is distinctly to occupy space, to have a physical presence in the world. Walking down the street, I square my shoulders and covertly measure myself against other men. Walking past a group of punk youths late at night, I wonder if I look formidable enough" (1985:83). Other acts, such as drinking, fighting, and sexual relationships based on male force are examples of other bodily performances of 'hardness' through which young men signify a particular hegemonic working-class masculinity (Canaan 1996). Through bodily expression, men compare their strength and ability to other men to "prove" they are masculine.

Black Men and Masculinity

Regardless of the dominant ideology in our society of "color-blindness" and equal opportunity, blacks experience high levels of inequality in their everyday lives. Their documented levels of education, income, standards of living, and job opportunities all suggest that systematic oppression occurs at many levels (Spraggins 1999). These levels of inequality and a dearth of legitimate avenues for black men to earn a living may hold

implications for expressions of masculinity, privileging expressions which may be at odds with the mainstream, white-collar society (hooks 2004; Spraggins 1999; Stier and Tienda 1993). Segal (1990) argues that black men are denied the "usual gender confirmations" applied to white men, and thus the self-destructive mechanisms of dominance manifest themselves in the form of the "gangsta" life or violence (hooks 2004). hooks (2004) sees "gangsta" life as a way for some black men to be a part of the capitalist marketplace when legitimate avenues, such as employment, are blocked. It is manifested through the use of violence, drug sales, and similar activities. Blocked economic opportunity, cultural devaluation, and the expression of masculinity combine to situate black men in a place of powerlessness in American society. They sometimes seek to overcome this sense of powerlessness via gun use and ownership (Spraggins 1999). Anderson (2000) presents a "code of the street" thesis, combining cultural and social explanations when explaining the high rates of violence among black adolescents. According to Anderson, the street code, including violence and gun use, is a cultural adaptation to the negative structural conditions prevalent in black communities. Stewart and Simons (2006) found support for this hypothesis and note that family characteristics, neighborhood context, and racial discrimination directly influence whether adolescents adopt the street code, which is similar to hook's "gangsta culture." These alternate means of accessing capitalist ideals allow blacks to create an alternative masculinity.

According to Hunter and Davis (1992), black men have unique responses to their social worlds because of the duality of their identities. These men are “moving between majority and minority cultures” and “must survive in a context of economic and racial oppression” (Hunter and Davis 1992:477). Their responses may produce what Connell (1995) identifies as marginalized masculinities – masculinities with characteristics that the dominant group devalues, such as alternative means for participating in the capitalist society as discussed previously. Kaufman (1990) explains that masculinities signify relations of power among men and not just of men over women. Because of this, a black man who has little social power in mainstream society might hold tremendous power in his neighborhood at the same time. He might have power over women of his own class or social grouping, or over other males of lower social standing in the community. Black men experience masculinity in a unique way that requires them to alternate between being powerless in the mainstream society and holding power within their own communities.

Accordingly, dealing with the complexities of life as member of a minority group in a majority society may require special talents, skills, or coping mechanisms (Johnson and Greene 1991; Pierre, Mahalik, and Woodland 2002; Spraggins 1999). These skills, talents, and coping mechanisms exist to reduce the psychological effects of constantly facing high levels of inequality in society. Majors and Billson (1992) name the coping

mechanisms that black men use to adapt, survive, and express themselves as "cool pose." They define cool pose as:

> presenting to the world an emotionless, fearless, and aloof front [which] counters the low sense of inner control, lack of inner strength, absence of stability, damaged pride, shattered confidence, and fragile social competence that come from living on the edge of society (1992:8).

Majors and Billson argue that cool pose helps "individuals adapt to environmental conditions and neutralize stress…being cool enhances the black man's pride and character, helps him cope with conflict and anxiety, and creates an avenue for expressiveness in entertainment, rap-talking, break dancing, and street cool" (1992:8). These mechanisms serve to present the world with a dehumanized and emotionless mask that creates some sense of stability in a system that is unstable and unsupportive. By appearing strong and stoic on the outside, they conform to the stereotyped versions of hegemonic masculinity without the resources to actually fill the position.

Black men construct multiple masculinities, but at the ideological level, this diversity is reduced to a monolithic form of masculinity that stands counter to the hegemonic white norm. Mainly as a consequence of racism, black masculinity has long been ideologically associated with a hyperphysicality that involves physical strength hyper(hetero)sexuality, and physical violence (Davis 1982). Black men are expected to conform to the expectations of mainstream culture – success, competition, and aggression – as well as requirements of the black community that may often conflict, such as

community involvement (Pierre, Mahalik, and Woodland 2001). The messages associated with hegemonic masculinity may be linked to the broader sociological and economic forces that undermine the development and appropriate expression of manhood among black men (Pierre, Mahalik, and Woodland 2001).

Disability in the Sociological Literature

Like gender, disability can be examined as a social construction. Sociologists have included disability in the sociological framework in various forms. Early works (cf. Goffman 1963) framed disability and impairment through the discussions of inequality and deviance. More recently, researchers have focused on the social construction of disability (Darling 2003; Reeve 2002; Thomas 2004), definitions of disability (Ormel, VonKorff, Ustun, Pini, Korten, and Oldehinkel 1994), and ways to study disability (Shakespeare 1999b). An increased awareness of the need to study disability in the cultural, social, and academic worlds is making way for an expanded discussion of disability in our society over the past decade.

The discussions about disability are expanding within social and academic fields, yet the existing literature detailing the relationship between disability and gender is sparse. Researchers have recognized that there is a pattern of ignoring gender in chronic illness and disability research. Smith and Hutchinson (2004) recently published an anthology, *Gendering Disability*, to promote the vital intersection of the two fields. Other studies have examined the ways that gender stereotypes influence the rehabilitation

process (Gerschick 1995; Meekosha 2004; Nosek and Hughes 2003) and how the gender identities of people with disabilities are “more complex and varied than the stereotyped views presented in the literature” (Shakespeare 1999a:55).

As portrayed in the literature, media and other social institutions often represent people with disabilities as not having a gender, portraying them “as freaks of nature, monstrous, the ‘Other’ to the social norm” (Meekosha 2004) and as asexual beings (Gerschick and Miller 1995). Yet the actual image of disability may be intensified by gender. For women, disability could intensify a sense of passivity and helplessness, while for men, their masculinity could be “corrupted” as a result of enforced dependence (Gerschick and Miller 1995). Moreover, these images have very real consequences in terms of education, employment, living arrangements, and personal relationships that then in turn reify these images in the public (Fine and Asche 1988; Meekosha 2004). The existing literature that examines the intersections of gender and disability focus on the images and stereotypes of people with disabilities and how inequalities based on gender can be further intensified by disability.

Most works examine the intersections of disability and gender focus on the experiences of women, while only a few explore the intersection of masculinity and disability (Gerschick 1995; Gerschick and Miller 1994; Shakespeare 1999a; Sparkes and Smith 2002; Tepper 1999). A few patterns exist among these works. First, they highlight the multiple perspectives of masculinity and sexuality. Second, they examine how people

with acquired disabilities challenge or rethink the normative idea of masculinity. Additionally, the existing literature about gender and rehabilitation demonstrates how men who experience catastrophic injury turn to more public and outward-looking opportunities during rehabilitation (Meekosha 2004) and their therapies often assert traditional masculine identities (Gerschick and Miller 1995). One example of this is the encouragement to engage in contact sports, such as wheelchair rugby.

Men with disabilities, who are not able to behave in stereotypically competitive masculine ways may adopt a variety of strategies to cope with the stigma they experience from others. Such responses include redefining masculinity as financial autonomy rather than physical prowess; building physical strength in areas of physical capacity (the 'supercrip' phenomenon[5]); or creating alternative masculine identities that stress personhood rather than gender roles (Gerschick and Miller 1994). These responses are similar to the creative ways that black men create alternative masculinities in opposition to hegemonic masculinity.

Opposing the image of the "supercrip" are the depictions of a person with a disability as weak, incompetent, dependant, ill, and impotent (Butler and Bowlby 1997; Valentine 1999). As Connell argued: "the constitution of masculinity through bodily

[5] "Supercrip" is a common term within the disability community used to describe a particular portrayal of people with disabilities. There are two themes to this narrative: 1) the idea that people with disabilities should be admired because they are "superheroes" just by participating in everyday activities (living independently, dating, going to school, holding a job) and 2) the image of people "overcoming" their disabilities to achieve superhuman feats that most able-bodied people do not attempt, such as a blind man hiking the Appalachian trail or performing a ballet in a wheelchair.

performance means that gender is vulnerable when the performance cannot be sustained – for instance as the result of a physical disability" (1995:54). Disability as a result of paralysis constitutes emasculation of a more direct and total nature (Valentine 1999). According to anthropologist Robert Murphy, the "weakening and atrophy" caused by paralysis "threaten[s] all the cultural values of masculinity: strength, activeness, speed, virility, stamina, and fortitude" (Murphy 1990:94 cited in Gerschick and Miller 1995:183). The common narratives of masculinity and disability in research and popular culture are often at odds with one another, and recent research has started to examine these conflicting stereotypes of "man as strong" and "disabled as weak."

The discussions of the intersections of disability and gender are growing. However, most of the literature, both traditional and progressive, fails to explore the differences inherent in disability and the way oppression variously affects identity and opportunity for different groups, especially minorities (Shakespeare 1999b). For example, being a black disabled person does not necessarily mean that the person experiences a "double oppression"(Stuart 1992). Stuart suggests that disability is part of a simultaneous experience of oppression and that these simultaneous experiences marginalize disabled blacks from "mainstream society" based on their race and ability. From the standpoint of a black researcher, Stuart says the notion of a double oppression comes from "without" and is based on the experiences and expectations of whites. Because of this, the oppression blacks with disabilities face is a singular level of oppression from able-bodied

blacks. A critique of Stuart's research is that it does not examine power relationships within the disabled community. Vernon (1997) responded to Stuart by stating that more empirical research is needed to examine the lived experiences and power relationships from multiple intersections. Vernon (1997) says the little information there is regarding the experiences of minorities focuses solely on rates of acquisition, causes, and occasionally the mention of the discriminatory nature of the disability rights movement.

O'Toole (2005) offers some reasons for the lack of research on the intersections of race and disability. First, there is a sexist and racist inheritance to the disability rights movement. The common face of a person associated with disability in America is a white man. Yet, white men do not suffer from the structural barriers in society at the same levels as do women and minorities. O'Toole (2005) makes it clear that those who fund research marginalize researchers who deviate from the accepted image of the mainstream white man in a wheelchair. There is a federal initiative to include more race-related research about disability in areas that are lacking, such as the importance or significance of marriage, relationships, or community involvement for those with SCI, and the exploration of the differences in these areas for racial groups beyond reporting descriptive statistics (Putzke, Hicken, and Richards 2002). The levels of exclusion based on race that are pervasive in other areas of society have also influenced scholarship on disability. Putzke, Hicken, and Richards (2002) are hopeful that available funds in this arena will encourage more researchers to study these important intersections.

CHAPTER III: METHODOLOGY

Sample Characteristics

This is a qualitative study involving in-depth interviews with ten white and ten black men with a noticeable physical disability. A noticeable physical disability includes the use of a mobility device (walker, cane, or wheelchair) or a significantly altered gait. Most of the respondents (n=18) had a Spinal Cord Injury, one respondent is a double above-the-knee amputee, and one respondent had physical limitations similar to SCI as a result of a neurological disease contracted in his twenties. Of those with Spinal Cord Injuries, an equal number of respondents were tetraplegic (n=9) and paraplegic (n=9). Although these respondents fall into the dichotomous medical designations of quadriplegic and paraplegic, there was variation in ability and function within these two groups. Table 1 shows a complete list of injury characteristics for this sample.

The age of respondents ranged from 24 to 67 years old with a mean of age of 38. The time since injury ranged from four to 21 years. Half of the respondents had at least a four-year college degree; nine others had a high school diploma. Employment is a real barrier for these men. Of the men I interviewed, only three were employed, one of whom was employed on a part-time basis. At the time of their injuries, 17 were either employed or attending school full time. One respondent had already retired and the remaining two were unemployed. Most respondents (n=14) were single or divorced and of the six that were married, three were with the same spouses that were with them at the time of injury.

Table 1: Respondents' Injury Characteristics

	Pseudonym	Level of Impairment	Age at Time of Injury	Years Since Injury	Cause of Injury	Place of Interview
Black Respondents	Anthony	Paraplegic	29	12	Auto Accident at fault	Hospital
	Charlie	Double Amputee	20	13	Gunshot	Home
	Darren	Tetraplegic	21	21	Auto Accident not at fault	Telephone
	David	Paraplegic	30	10	Auto Accident at fault	Hospital
	Larry	Tetraplegic	34	6	Auto Accident not at fault	Home
	Miles	Tetraplegic	24	4	Auto Accident not at fault	Hospital
	Philly	Paraplegic	21	5	Auto Accident not at fault	Home
	Robert	Tetraplegic	18	22	Diving Accident	Home
	Taylor	Paraplegic	20	12	Gunshot	Home
	William	Paraplegic	20	21	Gunshot	Office
White Respondents	Allen	Tetraplegic	63	4	Fall	Home
	Bill	Quadriplegic	21	25	Viral Infection	Hospital
	Bobby	Tetraplegic	22	13	Fall	Hospital
	Brendan	Tetraplegic	18	6	Auto Accident not at fault	Home
	Brian	Paraplegic	31	6	Auto Accident at fault	Home
	Chris	Tetraplegic	23	7	Diving	Hospital
	Ethan	Paraplegic	22	11	Auto Accident at fault	Home
	Gary	Tetraplegic	49	5	Boating accident	Hospital
	Kirk	Paraplegic	32	11	Auto Accident unknown	Hospital
	Mike	Paraplegic	22	6	Work-Related	University

Mean Age at Time of Injury	27
Mean Number of Years Since Injury	11

Table 2: Respondents' Demographic Information

	Pseudonym	Current Age	Highest Level of Education	Marital Status	Children	Work at Time of Injury	Currently Employed?
Black Respondents	Anthony	41	High School	Married pre-injury	Yes pre-injury	Truck Driver	No
	Charlie	33	High School	Single	Yes post-injury	Manual Labor	No
	Darren	42	College	Married post-injury	Yes post-injury	Manual Labor	No
	David	40	High School	Married post-injury	Yes pre-injury	Skilled Labor	No
	Larry	40	Less than High School	Single	No	Manual Labor	No
	Miles	28	High School	Single	No	Unemployed	No
	Philly	26	College	Single	No	Military	No
	Robert	40	College	Single	No	Student	No
	Taylor	32	High School	Single	Yes post-injury	Unemployed	No
	William	41	Beyond College	Married and divorced post-injury	Yes post-injury	Student	Yes Full Time
White Respondents	Allen	67	College	Married pre-injury	Yes pre-injury	Retired	No
	Bill	46	College	Divorced post-injury	Yes post-injury	Student	No
	Bobby	35	High School	Single	No	Manual Labor	No
	Brendan	24	High School	Single	No	Manual Labor	No
	Brian	37	High School	Married post-injury	No	Carpenter	No
	Chris	30	College	Single	No	Drafter	Yes Full Time
	Ethan	33	College	Single	No	Military	No
	Gary	54	College	Married pre-injury	Yes Pre-injury	Government	No
	Kirk	43	College	Divorced pre-injury	No	Sales	Yes Part Time
	Mike	28	High School	Single	No	Manual Labor	No

Mean Age	38

Three of the single men were married at the time of injury and those relationships have since ended. Nine of the respondents have children. Table 2 shows the demographics of my respondents.

I used convenience sampling as the primary method for identifying respondents. I began my recruitment process by speaking with the sports team coordinator and peer support coordinator at a specialty, catastrophic care hospital in a large southern city. This hospital is the largest of the sixteen model spinal centers in the nation, treating more than 200 SCI patients a year. A model SCI center is one that works with other model SCI centers to demonstrate improved care, maintain a national database, participate in independent and collaborative research, and provide continuing education relating to spinal cord injury (Model Spinal Cord Injury System Dissemination Center). The center also treats patients living with Multiple Sclerosis and Acquired Brain Injury (ABI). After receiving permission from the peer support coordinator, I posted flyers in common areas of the hospital and made announcements at the hospital's peer support counseling group for former patients and to sports teams affiliated with the hospital. I also encouraged my respondents to refer others who might be interested.

Data Collection

Following approval from the University's Institutional Review Board, I collected data using in-depth, face-to-face, open-ended interviewing, which I conducted in a setting of the participants choosing. Eight interviews took place in a room within the hospital

and I conducted nine interviews at the respondents' homes. I conducted one interview at a local university, one at a participant's place of employment, and the final interview took place over the telephone due to travel constraints. I provided each respondent with a consent form to review and sign after I explained the goal of the study. The respondents signed two copies of the consent form and they kept one copy for their records.

The interviews loosely followed an interview schedule (see appendix c). I addressed major topics related to masculinity, sexuality, work, family, and public perceptions. As I interviewed more participants, I found myself disregarding my interview schedule and opting for a less structured, interactive interview process. I did this in part because questions I thought the participants would not feel comfortable discussing with me, such as sex, I placed later in the interview schedule. Conversely, most respondents brought up the subject within the first thirty minutes of the interview.

I was concerned about my status as an "outsider" during this process. As a white, non-disabled female, being an insider to a group of disabled men could be quite difficult. However, I found that my respondents spoke openly about their experiences. My status as a partner to a man with a physical disability allowed me to gain entry to the group and to identify with some of the experiences they discussed. My insider-outsider status also provided for many in-depth conversations about experiences that we might not have explored had we shared the same vantage point.

All the interviews were recorded. The respondents were in control of the tape and could pause or discontinue the recording at any time if they felt uncomfortable. Each interview lasted between one and two hours. Two respondents had difficulty speaking of some memories due to the emotional nature of them. In those instances, we paused the recording and I provided the respondent with a period of silence. After the respondent appeared to regain composure, I provided them with the opportunity to discontinue the interview. Both respondents wanted to continue. Both of these exchanges were difficult for me, because I was not sure how to react or respond. One of the respondents sent me an e-mail the following day apologizing for his emotions, stating that he had decided not to share his emotions with anyone else again. I was concerned that I did not provide a safe space for this respondent. After further communication, he explained that it was not my handling of the situation, but rather, as he described it, his “inability to stay strong.”

Research Questions

In recalling the nurse’s response to my partner’s grief, this study focused on the following main questions. How do men experience life with an acquired disability? Are there experiential differences (grief, adjustment, community response, etc.) between black and white men and white men? During the interview process, I asked questions about life experiences before injury, during the rehabilitation process, and over time since leaving the hospital. Questions centered on themes such as definition of self, peer groups, community responses, masculinity, sexuality, employment, and how their race might be a

factor in any one of these areas. I guided interviews in a manner to capture the unique experiences of men with acquired disabilities. By taking this approach, I add to the existing literature regarding disability by expanding the social inquiry to include the men who have not had their voices heard in the existing literature.

Data Analysis

Qualitative research methods are effective when the goal of the research is to understand how individuals make meaning of their lives (Berg 2001; Miles and Huberman 1994; Strauss and Corbin 1998). Qualitative data enable us to know how individuals arrive at meanings, live as social beings among many, interact with others, and maintain boundaries, which help define them as individuals(Stone and Priestley 1996). The goal of the qualitative method is "to explicate the actual social processes and practices organizing people's everyday experience from a standpoint in the everyday world" (Smith 1987:151). Based on these assumptions, the different experiences of men with disabilities can be best captured using a qualitative approach. This is an exploratory study, in which the realities of black and white men's experiences with acquired disabilities are clarified through description and traditional qualitative analysis. The goal of this research is to understand experiences of disability through in-depth interviews with black and white men.

In order to understand these experiences, I relied on traditional qualitative data analysis techniques to explore themes and concepts in the data. This technique requires

"coding," memo writing about the research process, and narrative analysis in order to give meaning to words and thoughts of my respondents (Miles and Huberman 1994). I used this technique primarily because, according to Miles and Huberman (1994), it is the meanings, not the words themselves that matter. There are many analytical options available to the researcher; however, I followed guidelines set forth by Miles and Huberman (1994).

The first step I took when analyzing my data was to organize and identify pieces of my respondents' narratives into "codes" that I could then compare and contrast. Codes are markers used to attach meaning to the material collected during data collection (Miles and Huberman 1994). Miles and Huberman (1994) present three types of coding: descriptive, interpretive, and pattern. Descriptive codes require little interpretation and the researcher often uses descriptive coding in the early stages of analysis. Interpretive coding requires that the researcher examine the data more closely and begin thinking about the complexities of the code and its relationship to other descriptive codes. The process of descriptive and interpretive coding, which occur simultaneously, gave me an overall understanding of the data I had collected and allowed me the flexibility to either collect more data until no new codes appeared or to modify my interview guide to explore something that a respondent brought up.

The third type of coding I employed was pattern coding. The purpose of pattern coding, according to Miles and Huberman is to "identify an emergent theme,

configuration or explanation" (1994:69). As this type coding progresses, it is important for the researcher to "qualify" the code. According Miles and Huberman, a code is qualified when "the conditions under which it holds are specified" (1994:71). Meaning that the researcher asks a series of "if-then" questions about the data, and if the pattern holds, then the code is qualified. If the pattern fails to hold, then the researcher must examine other explanations. This is similar to Corbin and Strauss' (1998) explanation of axial coding, during which the researcher compares categories to each other to see how they relate.

I also engaged in memo writing during the coding process. Miles and Huberman (1994) use Glazer's (1978) definition of what a memo is: "the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding" (72). Miles and Huberman (1994) explain that memo writing is one of the most "useful and powerful sense-making" tools available to the researcher (72). Memoing is a way for a researcher to sketch ideas about what direction the analysis might take, reflect on the coding process, explain why certain codes were used, and provide an overall structure to the analysis (Miles and Huberman 1994). I wrote memos after interviews, during data analysis, and while writing the results. For me, memos were a way to remember important points or to try to understand the meaning of the codes. I found the process of memoing most helpful when structuring the chapters. I also used memoing to examine similarities and differences between whites and blacks, level of function, and age when

analyzing specific themes. Memoing was also helpful when I was trying to understand a phenomenon when there was not any existing literature to guide me.

Finally, I developed a narrative analysis. Maxwell (2005) suggests that there should be a way to break the categories apart and put them back together in order to produce a story of the researcher's findings. This is achieved by identifying one thread that runs throughout the entire story. Within this project, I suggest that constructions of masculinity and disability push and pull at one another in the experiences of these men's lives.

Data Reliability and Validity

The nature of qualitative knowledge and truth can be very different from the nature of non-qualitative truth and knowledge (Rosenblatt and Fischer 1993). Because of this, standard methods of establishing validity and reliability are not as applicable in qualitative research as they are in non-qualitative research. I will discuss the methods that are applicable to qualitative research in this section.

Validity in qualitative research is concerned with bridging the gap between a concept and the data. Qualitative researchers seek authentic meanings and accounts of social life from the perspective of those who live it every day. As validity generally means truth, qualitative researchers try to gain an understanding of the true experiences of the people they are studying (Kirk and Miller 1986).

Miles and Huberman (1994) discussed validity in terms of “verification.” Verification takes place continuously during data collection and analysis. When a finding begins to take shape, the researcher checks it out in subsequent interviews. Validity checks occur when meanings emerging from data are examined for their plausibility and their conformability. Without this step, we are left with interesting stories of what happened, of unknown truth and validity.

According to Miles and Huberman (1994), a researcher can practice verification in two ways. The first way can be as brief as having a “fleeting thought” during analysis, which sends the researcher back to the data for a second look. The second way, as suggested by Miles and Huberman (1994), is a more thorough and complex process. It involves lengthy argumentation and review with colleagues to develop “intersubjective consensus.” Although I was the only researcher on this project, I did find ways to discuss my preliminary findings with other graduate students and members of my committee. I also took advantage of opportunities to present preliminary findings at regional sociological conferences. At these presentations, audience members questioned my interpretations and introduced alternative ways of viewing the data.

Reliability is related to validity in qualitative research. According to Stenbacka (2001) the issue of reliability concerns measurements, therefore it has no relevance in qualitative research. She adds that when judging the quality of qualitative research, the issue of reliability is irrelevant. By examining the concept of reliability in a larger context

we can see similarities of reliability and validity in qualitative research. Lincoln and Guba (1985) state that "since there can be no validity without reliability, a demonstration of the former [validity] is sufficient to establish the latter [reliability]" (p. 316). Furthermore, the validity and reliability of qualitative data depend to a great extent on the methodological skills, sensitivity, and integrity of the researcher (Guba and Lincoln 1981; Patton 2002).

Qualitative research does not easily follow the standards of reliability and validity by which quantitative research is usually evaluated. Denzin and Lincoln (1998) suggested two potential sources of invalidity for interviewing in qualitative research: the interviewer's identity and the relationship between the interviewer and subject. The interviewer may attempt to translate her own stance on interview topics into the interaction process. During this project, I had to question my own family experiences with acquired disability, and, while those experiences guided the choice in research topics, I attempted to make sure those ideas are not the only ones I examined in the course of this study. I needed to be extremely aware and cautious about the influence of my own attitudes and my partner's experiences with an acquired disability. Conversely, these experiences provided an opportunity to obtain richer insights from the collected data to add a subjective dimension to this research (Fonow and Cook. 1991).

Conceptual Frameworks

Based on my review of the literature and my overarching research questions, I used two theoretical frameworks during the course of this study: symbolic interaction theory and the social constructionist perspective. I discuss both of these frameworks as they relate to this study about the meaning and experience of physical disability for men.

Symbolic Interactionism

Symbolic interaction is a theoretical perspective conceptualized by Blumer (1969) that stems from the earlier writings of Cooley (1902), Mead (1934), James (1890), and Thomas (1972). Symbolic interaction is useful for understanding the processes, interactions, meanings, and interpretations of various social phenomena (Blumer 1969). It includes the assumption that humans live in a symbolic and physical environment, and as such, we acquire complex sets of mental symbols, which give meaning to people's interactions (Rose 1962). Furthermore, symbolic interaction provides guiding principles of qualitative inquiry for researchers who want to study and interpret human group life and behavior.

Blumer (1969) stated that symbolic interaction rests on three premises: meanings, social interactions, and interpretations. First, according to Blumer (1969), human beings act toward things on the basis of the meanings things have for them. Second, he argued that meanings are social products formed through interaction with other people. Third, he stated that meanings and interactions among individuals are handled in, and modified

through, an interpretive process, in which each person deals at varying degrees with the things they encounter in everyday life. Blumer also stated that interpretation should not be regarded as an automatic application of established meanings. Instead, interpretation is a formative process in which meanings are used and revised as instruments for the guidance and formation of action.

These three premises illustrate that people perceive events, culture, identities, etc. through what they do (Blumer 1969:8). For example, if a person expects that life with a disability cannot be meaningful, that expectation may shape their actual experience. Also, using a symbolic interactionist perspective leads to further questions about the negotiation of identities (LaRossa and Reitzes 1993). After a catastrophic injury, like other major life events such as divorce or the death of a close family member, some level of identity redefinition must occur. How well injured people adapt or adjust to their new circumstances and understanding of both their situation and themselves may determine how well they interact with family and peer networks.

Additionally, four symbolic interactionist concepts are also important to this research: (1) identities, (2) roles, (3) interactions, and (4) contexts (LaRossa and Reitzes 1993). *Identities* are defined as self-images in a role and are hierarchically organized by salience. In other words, “identities and salience are two ways that individuals use self-conceptions to motivate their actions” (p. 145). Salience is influenced by a persons

commitments (Stryker 1969). Commitment refers to the “cost” of giving up social interaction, a line of action or identity (LaRossa and Reitzes 1993)

Roles refer to “shared norms applied to the occupants of social positions” and “specify not only knowledge, ability, and motivation” (LaRossa and Reitzes 1993: 147). Roles may vary in relation to their social position. Some roles are formal and refer to positions in social organizations or groups. Examples of formal roles would be father or employee. Informal roles, such as best friend, are usually identifiers of interpersonal or interactional positions that are not usually understood by outsiders.

Regarding *interactions*, LaRossa and Reitzes (1993) state, “it is through social interaction that individuals apply broad shared symbols and actively create the specific meanings of self, others, and situations” (p. 149). The presentation of self in everyday life requires the use of verbal and nonverbal indicators to convey one’s role and identity, while simultaneously inferring how others are receiving and responding to the presentation (LaRossa and Reitzes 1993). The “drama” that occurs because of social interaction stems from the fact that the individuals who are performing are aware that others are assessing their presentation. Therefore, impression management operates on several levels of reflexivity (“I am aware that you are aware that I am aware.”) (LaRossa and Reitzes 1993).

Symbolic interactionism also pays attention to the connection between individuals and societal *contexts*, understanding this connection can be complex. Strauss (1978)

explains the “negotiated order approach” to social organization with three concepts (qtd. in LaRossa and Reitzes 1993:152). The three concepts are negotiation, negotiation context, and structural context. *Negotiation* refers to the many ways to accomplish the goals (e.g., independence). *Negotiation context* constitutes the “structural properties that enter most immediately into the course of negotiation” (e.g., negotiation between independence and needing assistance with personal care) (p. 152). *Structural context* denotes the society in which individuals negotiate (e.g., barriers to employment limit independence).

Interaction with others, perceptions of self, and the interpretation of meaning can be more complex if individuals think of themselves to be part of a deviant or stigmatized group. Goffman defines stigma as “an attribute that is deeply discrediting” (1963:3). The discrediting nature of stigma means that an individual who is stigmatized can affect how that individual will interact with others, and how others interact with that individual. The men in this study had noticeable physical disabilities, but they also had numerous conditions as a result of their injury, like erectile dysfunction, that they kept hidden for fear of being stigmatized further as abnormal men. Goffman suggests that the management of information regarding a stigma involves confusion when an individual is confronted with questions of who to disclose information to and whether they even should disclose the information in the first place. A stigmatized individual’s personal and social identities can be severely impacted by disclosing information, thereby dividing

social relations between the “knowing and unknowing” (Goffman 1963:66). Another aspect of Goffman’s concept of stigma is that certain people possess “courtesy stigmas,” which he defines as stigmas that are “spread from the stigmatized individual to his close connections” (1963:30). This is interesting when thinking about the dating and marital relationships of the men in this study. Their reasons for ending or not pursuing relationships often focused on not wanting to make women feel like “they had to deal” with a disability.

The Social Construction of Reality

The social constructionist perspective provides a theoretical framework for examining the objective and subjective realities of everyday life. Berger and Luckmann (1966), argued that humans, as social beings, respond to our definitions and interpretations of situations, not the situations themselves, thereby shaping reality. Berger and Luckmann’s theory of the social construction of reality is divided into three key components. First, they discuss the foundation of knowledge in everyday life. Second, they examine society as an objective reality in terms of how reality becomes institutionalized and legitimized over time and space. Lastly, they propose that society as a subjective reality centers on the internalization of reality in primary and secondary socialization.

Berger and Luckmann lay the foundation for the social construction of reality by theorizing about the reality of everyday life. They view the reality of everyday life as an

ordered reality. They elaborate on this by positing that everyday life is organized around various social interactions and the language used to transmit meanings. Social interaction in everyday life has an impact on how men experience a catastrophic injury. It is tied to the key idea that everyday life is structured both spatially and temporally. Age at the time of injury and the time passed since the injury are important elements to consider when trying to understand how men who experience a catastrophic injury create reality. Additionally, spatial structure is a key aspect to the social construction of masculinity and disability. If these men can gain access to spaces independently, they may feel more secure in their masculinity than when they must rely on others for access.

One application of the social construction of reality is the social constructionist theory of gender, which emphasizes the day-to-day production or "doing of gender" (West and Zimmerman 1987). Gender is about social interaction. According to West and Zimmerman (1987), gender is embedded in every aspect of everyday interactions. One's actions in doing gender simultaneously produce, reproduce, sustain, and legitimate the social meanings given to gender. One key aspect of "doing gender" is the notion of accountability (West and Fenstermaker 1995). Since society is structured according to a dichotomous sex categorization – male and female – doing gender is to make one's actions accountable in terms of their appropriateness to sex category (West and Fenstermaker 1995; West and Zimmerman 1987). For example, men try to live up to the social expectation of being strong and tough, and women try to be gentle. In effect, doing

gender has the effect of producing and reproducing the notion of “essential differences” between men and women (West and Zimmerman 1987).

The social constructionist theory of gender also suggests that gender is not a natural state of being. Rather, the meaning of gender shifts and changes based on the social context in which an individual is situated (West and Fenstermaker 1995). Gender is fluid, situational, and shifting though an individual’s interactions. The social constructionist theory of doing gender” is a useful framework to examine the performance of gender for men with disabilities, since it is commonly understood that “disabled man” is a self-contradiction, because men are supposed to be strong, tough, and able (Lorber and Moore 2002).

The next three chapters of this thesis use these theoretical frameworks as a basis for exploring and examining how these men experience disability. In the chapter immediately following this discussion, I examine how meanings of disability were created or modified through these men’s experiences. The next chapter explores how men act on these shared meanings, and their shared meanings of masculinity, to perform masculinity. They accomplish masculine performance by using impression management, especially as it relates to managing stigmatized aspects of their experiences. Finally, using the symbolic interactionist concept of context, I explore the connections of the individual and their larger social world. I examine how these men’s goals of masculine performance are situated in structural contexts.

CHAPTER IV: THE MEANING OF DISABILITY

Entering the world of catastrophic injury through my partner's accident, I found I had to question my understanding and preconceived notions of disability. I learned what SCI is and how it affects much more than muscular paralysis. In discussions with my partner and our family and friends shortly after the accident, we found that we had a high level of ignorance surrounding SCI and what information we had was often incorrect. What we knew about SCI shaped what we thought our future would hold. Knowing how much our understanding, or lack thereof, shaped our views of the rehabilitation process and subsequent return to the community, I wanted to know how other people's views shaped their understanding as well. Furthermore, I was interested in knowing how social interaction shaped these men's meanings of disability and how these meanings might be modified through their interpretations.

To examine what these men thought about disability and their every day life, I asked them what they knew about disability before their injury and how their views changed afterward. All but three of the respondents had never thought about disability, especially SCI, before they were injured. Respondents typically answered, "I never really thought about it," "I didn't know anything," "I had no… no clue whatsoever what spinal cord injury was," and "I was ignorant." After I probed further, I found that they had encountered people with disabilities and had a more developed idea of what they thought life with a disability meant. This chapter examines three themes that emerged about the

formation of the meaning of disability: disability as invisibility, hyper-visibility, and a ruined life. For each of these themes, I discuss the symbols that were used to create the meanings, how people acted toward them, and how they were modified through social interaction. I present these findings as background for understanding how these meanings influenced the men's construction of masculinity after their injuries, which are discussed in the two subsequent chapters.

Disability as Invisibility

The first of the three themes that emerged from the data relate to the common first response by the men in this study: "I never really thought about it." One reason these men did not really see, or think about, people with disabilities is the lack of available images. Robert, who was injured at the age of 18 when he dove into a shallow pool, explained:

> We have a lot of disability awareness where you see more disabled people out in society. You're able to see them [people with disabilities] on commercials, not as many as there should be, but it's a start. Seeing disabled people running companies. And I tell you, back in '85, it was a dark world to look into, and not see somebody that looks like you, in a chair, or disabled, out doing things.

Robert's injury took place before the height of the disability rights movement and the subsequent passage of the ADA. He says that currently, there are some people in wheelchairs on TV, but in order for disability to be visible and positive there needs to be more images.

After further probing, the respondents shared more about what they thought or did before their injuries when they saw someone in a wheelchair. Allen, a retired laborer

injured in his home, reflected on how he acted toward people with disabilities before his injury, using the perspective he has since acquired:

> I was probably guilty of the thing I hate the most… people either totally ignore ya, or stare at ya. And I was probably guilty of ignoring ‘em. You know, trying to act like they’re not there.

Ignoring people requires action and effort. As Allen says, he “tried to act like they’re not there.” By using this action, the meaning that disability should be invisible remains intact.

In the above quote, Allen says people either “ignore ya or stare at ya.” Likewise, Larry was afraid that he would be stared at when he left the hospital. He was injured in a car accident six years ago and said:

> You know, I used to be kinda embarrassed to go out in public. I was kinda shamed of who I was but when I start doing it, and realized wasn’t nobody paying no attention.

He thought because he looked so different, people would judge him. He did not want this extra attention because he was ashamed of himself and his new presentation of self. His new reality is that he is in fact invisible to others.

Like Larry’s desire to be invisible, 11 men reported that in the first weeks and months following their injury, they would find ways to ignore themselves. They avoided mirrors and reflective windows in an effort to maintain their self-image as not disabled. Chris, who was injured diving into a pool at night, describes a strategy he used to avoid images of himself during the first few weeks of rehabilitation:

> Somebody else was pushing me and I asked them to push me in [backward] so I didn’t have to look in the mirror in the elevator. I didn’t know why, I just didn’t want to see it at the time. You know?

> Really, out of sight, out of mind. Even though this is happening, and it's real, I didn't want to look in the mirror.

Like Allen, Chris actively found ways to make disability invisible. Chris knew he could not avoid images of himself forever because it was "real," but he could try, much like Allen tried to ignore strangers with disabilities. Both of these acts serve to create the reality that "out of sight, out of mind" is a way of reproducing the invisibility of people with disabilities in society.

Sometimes it was impossible for the respondents to ignore the reality of disability. In public, it was easy to walk away from, or position themselves, so they did not see images of themselves. But in private, it was not easy to escape this reality. Kirk, who was injured in a car accident on his way to a family vacation, recalled:

> Everyone was always worried that I was in denial. Because I never showed grief over it [the injury]. I just showed acceptance, I accepted it. Now, the reality is, I cried three times. The first time I was lying in bed after my first day of rehab, and if you look at the back of the wheelchairs in here, they have the person's name in masking tape across the back of it…and I saw my name on the back of the wheelchair, it was across the room. And I looked at it; it was my first or second night here. I just…cried. I cried through the night. And, next day it was over…

The experience of seeing his name on his own wheelchair, a symbol of disability, made this new reality visible and unavoidable.

Within the context of interactions with strangers, the respondents found that strangers attended to the symbols of disability, rather than the disabled people

themselves. These symbols include the wheelchair and "good" parking spaces. Bobby, who was injured when he was 22, describes how strangers do not see him:

> I don't know. Most of the time…I don't think they [strangers] see us at all…I've said hello to people in Wal-Mart, they go right on by. Just not even bothering to acknowledge [me]. But yet, they love them handicapped spots.

Choosing what to attend to in this interaction, parking space versus person, is another way to send the meaning that a person with a disability should be invisible. The positive aspects of a disability, such as good parking spaces, are worth attending to while negative aspects, such as the loss of mobility, are not. In the above interaction, Bobby feels invisible because he embodies the negative aspect of disability.

Wheelchairs are other objects that are attended to over the person. Kirk, who reacted to the visibility of his wheelchair in an earlier excerpt, recalled an encounter with a former friend during his first outing in the community:

> I saw a couple who I had introduced to each other…years earlier. And, actually, me and this guy had been pretty good friends…I had been the one who introduced them and they ended up getting married and have three kids. I saw them at the game…he walked by me three times getting beer…I knew it was him…when he came back from the third trip, I went – hey, hey, hey, trying to grab his attention to say hello to him. And, he saw the chair, but he didn't see me. And I felt so, so put out by this fact. That this guy, who I had had a major effect on his life…and have [him] not see me, but see the wheelchair. It hurt. It wasn't enough to make me cry or anything like that, but I was really hurt by this fact, and the realization that came from it, that, you know, how he obviously knew that it was a wheelchair, there at the end, and he tripped over my feet once. And not to see who was in the chair, but to see the chair itself.

The wheelchair is a visible symbol of disability. When people pay attention to the wheelchair and not the person in the chair, they send a message to the person with a disability that they are no longer the visible and active participant in the interaction.

Social interactions serve to further form and reinforce meanings. In the case of invisibility, ignoring people with disabilities serves as a way to create and act upon the meaning that disability is something that should not be talked about or made visible. According to Zola (1984), the social invisibility of people with physical disabilities has a more subtle development than the stereotyping or invisibility of racial or ethnic groups. This is in part because when small children see a person using a wheelchair or cane, or wearing a brace, they are curious and often question their parents. It is during this interaction that parents teach their children to ignore what they are seeing. In doing so, children learn to ignore the whole person, not just the characteristic that makes the person different (Zola 1984).

All of the men in this study reported at least one example of feeling invisible in social interactions. One frequent example of this was when strangers would “talk around” a person who uses a wheelchair. This happens on dates, in doctors’ offices, and in other public spaces. When strangers “talk around” them, it makes these men feel like they are even more invisible than an interaction that does not require engagement, such as passing them in a parking lot. This behavior is also very emasculating, especially within the context of dating, where actions such as ordering and paying at restaurants are typically

relegated to the man. Gary, whose injury occurred because of a boating accident, describes a common interaction:

> They'll still ask [my wife] what I want. Excuse me, I'll order...they give her the bill too…I get my wallet out and give her my card and they come back and I have to sign it. It's a cute process.

This interaction sends the message to Gary, that he, as a disabled man, is not visible. Furthermore, he is not able to fill the role of provider by paying for a meal. Instead, his wife now has that role. By playing into their stereotypes, giving his wife the card to pay, he allows this meaning to stay intact. However, when he signs the receipt in their presence he is making himself a visible and active agent in the interaction.

Robert provides another example of how this action takes place. He excuses this action because he assumes that the person talking around him assumes he is mentally disabled and that might require a different interaction:

> Being disabled, a lot of times, society looks at [you like] you're just mentally disabled… what I'm trying to say is that, there have been times when I go to a doctor's appointment in my early stages, with my mother. And they'll say, 'How's Robert today? How's he feeling?' And I'm sitting right there. I can talk, I can hear you and, my mom'll say, 'you can talk to him, there ain't nothing wrong with his mind.'

Like Gary's interaction in the restaurant, Robert's situation required intervention to show he is capable of being a part of the interaction. Gary would sign the receipt, and Robert's mother would inform the receptionist that her son was mentally capable of answering a question. In both of these interactions, the subtle nature of their resistance quietly challenges the notion that they are invisible.

There are times that subtle interactions, like those just discussed, are not enough to modify the meaning that disability is invisible. In these cases, respondents take advantage of the interaction to create a dialogue about SCI and disability in society as something visible. Sometimes they engage in a conversation and other times they try to be a positive example. For instance, Gary explains that when someone ignores him or gives his wife the bill, he assumes they just are not aware. He says:

> I think they're just not educated. So I have to right on the spot give 'em a quick education. Especially in restaurants.

This "education" often includes speaking up to the server and saying, "Excuse me, but I can order" or trying to engage them in a conversation. Engaging in conversation provides for an opportunity to modify the meanings about the ability of someone who uses a wheelchair.

Charlie, whose best friend shot him at the age of 20, summarizes how this interaction between him and children takes place when they ask about his missing legs:

> And their parents be like 'Don't ask that, that's rude.' And I'm like 'No, it's not rude. They don't see this everyday. Let me explain to 'em in a way that they can understand.' It just depends on what they age are. Let me explain to 'em what happen and and why the doctors had to remove my legs and stuff like that and we just end up talkin' right there in the entrance of the mall or wherever we at and nine times outta ten the parents be curious too, so they sit there, they listenin', you understand?

This interaction creates room for these children and their parents to form new meanings about disability. As Blumer (1969) states, the interpretation of meaning, in this case "don't ask," should not be an automatic application of set meanings. Rather,

interpretation should be a process in which meanings are modified as tools for guiding future action. Charlie is hopeful that by creating this space for discussion about his disability, rather than avoiding it, he can shape new meanings for these children and their parents so that the next time they encounter someone with a wheelchair or cane, they do not shy away from the person with a disability and treat him or her as if they are invisible.

Disability as Hyper-visibility

The second theme that emerged from the data was that having a disability meant that they were hyper-visible. This meaning was formed by the ways that these men were treated and looked at by others. While "disability as invisible" occurred by ignoring the person with a disability, the application of hyper visibility relies on staring and extra attention.

Brendan offers a unique experience to the difference between invisibility and deviance. Brendan has a cervical spinal injury; however, his level of function is such that he is able to ambulate with the use of leg braces, which causes an exaggerated limp, and a cane. For longer distances, he uses a wheelchair to reduce fatigue and protect his joints from injury. He explains:

> People treat you differently. When I'm walking and people stare at me, it's different because when I am in the chair, people try not to stare. When I am walking, they just stare boldly. In the chair, I don't get weird stares like I do when I'm walking.

For Brendan, having an exaggerated limp and a difficult time maintaining his balance when walking generates more stares than when he is using his wheelchair. Using a wheelchair, a visible symbol of disability, excuses his difference. When he does not use his wheelchair or cane, he loses the symbols of disability and is stared at because he is deviating from the normal expectations of a person who has the ability to walk.

Brendan's experience of being stared at is unique because of his mobility, but it is not unique in the fact that six of my respondents report experiences of being stared at by strangers. William, who was a college student at the time of his injury, recalled one of his earliest outings after his injury:

> Once in a mall when I was recently in rehab, we were on an outing and this old white guy just stopped and stared at me. He didn't say anything, I didn't say anything. This is one of my first outings in the chair. That was the weirdest experience.

Men are not as accustomed to being stared at or visible in society as are women (Berger 1986). For William, it was an unnerving experience because he was now in a social position that involved being looked at, even when it is not socially acceptable to stare.

Being the recipient of the gaze is not limited to blatant staring. Half of my respondents reported they felt that people were overly friendly or attentive toward them. For example, Brian, who was involved in a car accident during a rainstorm, reported that he receives more attention in the chair than he did before:

> I just noticed that when I was in the chair, you'd get a lot more recognition. Where people try to be friendly, that, six years ago they wouldn't have given me a second glance. Which I find interesting. I don't know if they feel guilty, or if they know someone in a similar

> situation. And of course you get the quick glance and look the other way. But, like I say, I've seen quite a few people that've – 'hey, how ya doing'– things like that, and it's like – 'do I know you?'

Brian's quote highlights his visibility. People are friendlier to him now that he is in a chair, when before he would not have been a visible object. The wheelchair creates this visibility.

Philly has also experienced women who were friendlier to him because he uses a wheelchair, which he does not like. He says:

> I'm in the mall, and girls be comin up to me – 'hey, baby, you want me to push you around?' Stuff like that. I'm like – 'no, if you want to, you can walk me though.' That's about it. We'd laugh, we'd talk or whatever, but that's it. That kind of thing wouldn't happen if I was walking. Everybody'd be minding their own business. And, it attracts a lot of attention, and I hate attention.

Being visible because of a stigmatized identity changes how women interact with Philly. Women who want to help him approach him and this interaction makes him feel more visible. If he was walking or did not have a disability, women would not offer assistance. By offering this assistance they send the message that he is not an independent man and he requires attention.

Being the recipient of the gaze was not limited to interactions with strangers. Three men wondered how friends or family would look at them. Looking different or scary was a concern that Charlie had:

> I was thinking [about] my kids. How will my kids look at me?...will they say WOW – ohh dad, oh that's not my dad. Or be scared of me, or would their friends be scared of me. Would they be ashamed if I

> come to their school? Uh, would they be ashamed to be around me period.

In this situation, disability is not only visible, but it is negative and embodies a stigmatized identity. Goffman defines a stigma as "an attribute that is deeply discrediting" (1963:3). This stigma can affect how interactions take place between people with and without the stigmatizing condition.

Returning to peer groups comprised of people without disabilities highlights how these interactions are altered. Chris explains that when he returned to work after leaving rehab, his co-workers treated him differently:

> But, I don't think that [the injury] changed how they felt, they just didn't bust my ass as hard. They're still riding me and make fun of me, and it was fine because I'd make fun of them right back. I felt more at home when they were, because they weren't trying to hide it or be shy about it. I could tell they were holding back a little bit.

Chris does not think the injury changed the interaction, but it clearly did because they did not treat him the same as they did before his injury. They treated him as though he was fragile and could not handle the good-natured ribbing that he would receive as a "non-damaged" man.

In three cases, the men found it easer to have and maintain friendships with other people who use wheelchairs. The need to fit into the "ab[6]" notion of normality was erased when interacting with others who are in the same situation. Seeking new friendships reduced the need to compete with other men who were striving to meet the hegemonic

[6] "ab" is a term used as an acronym to refer to "able-bodied" people. It is commonly used among rehabilitation professionals and is a term that many of my respondents used.

ideals of masculinity. Ethan, who was injured in a motorcycle accident while serving in the military, explains why the wheelchair community is important to him:

> They [ab people] just were seeming like they were bringing me down. Because they were all bitching and complaining, yada, yada, yada, you know. I'm like, whatever, dude, I gotta go talk to this guy who has no hands or has no legs. And, and [I'll] smoke your ass at anything that we do. So I totally took myself out of that group…Hanging out, drinking, carrying on, doin' the whole, you know, twenty-three, twenty-four, twenty-five year-old thing. And, I was just like, it's not working for me anymore. You know, I like those guys, I love those guys. But, it just nothing will compares to people in chairs. I mean, they're already in a different, well, just something that they've had catastrophic go wrong. I mean, it's kind of weird that, that you look for people like that, but they're stronger. They're different. It's a different blend of people.

In this situation, Ethan has modified the meaning of disability as deviant. Having friends with disabilities is preferred because, for Ethan and the two others who used this strategy, they are stronger. Having friends who also have shared life experiences also makes those interactions more relevant.

Ruined Life

The third theme that emerged was that life could not be meaningful with a disability. In other words, having a disability equated to a ruined life. The meaning of disability as either invisible or deviant was most often applied to the outward presentation of self, while the meaning of disability as a ruined life applied to more active and complex aspects of these men's lives than the previous two meanings.

The men in this study recalled the images and interactions that helped form the meaning of a ruined life. In response to my probes about what they knew about their

disability before their injury, quadriplegics reported that not only had they not thought about it, but also that they did not think you could live with a broken neck. Bobby, a quadriplegic injured in a fall on a beach at the age of 22, describes his first reaction to his SCI as one that was shaped by the media portrayals of people who break their neck:

> I thought everybody that broke their neck died from it. I mean, you see it on TV, that, you know, when you're watching the movies, the guy reaches up, breaks another guy's neck, you know, just automatically dies. So, I, when I broke it, I heard everything pop, I was like, uh, [this woman I was with] said I was gonna kill myself over there [cliff diving], and she brought me to the beach to do it [die].

Death is a very powerful image and an extreme way to view how life is ruined, but it was common among these respondents.

Watching one's body go through physical changes can also equate to a ruined life. Philly, who describes himself now as a "light hearted, happy guy" who "loves life," did not think life was worth much right after his injury. A primary reason for that was because of the way his body changed after his injury. He was a "strong and fit" member of the military that turned into someone that did not embody physical force, a requirement for hegemonic masculinity. He describes how his body reminded him of the "worst day of his life":

> I used to hate my body. 'Cause it feels like it's a new body. I wake up one day and I'm put in a whole new body, and I'm getting a whole new set of rules…I didn't want to look at myself in the mirror. Nothing…I didn't even look. I didn't want to look at my feet, I didn't want to look at my legs, I knew I was losing weight. I didn't want to look at it. I didn't want to look at anything. I didn't want to look at my arms…Didn't want to look at my face…I didn't, I hated it, it was

> wrecked, it was wreckage…It was reminding me of the worst day of my life, every day. Every time I look at this, it's the worst day of my life, every day. It's like [the movie] *Groundhog Day*.

Philly did not want to look at himself after his injury because his body was a reminder of what he was losing. His body was "wreckage" and failure meant that he could no longer be the physical force that he had been before the accident.

In some of the other respondents, images of disability as a ruined life were not as extreme as the ones Philly described, but were instead imagined as a metaphorical death. Charlie, a 33 year old double amputee, recalled his initial thoughts after being shot to be, "Lord, please don't let me be paralyzed." When I asked him why, he responded:

> I had a friend [who was] shot like a year or two before I did and I was so ignorant at the time that I was thinking that I didn't want to live like that, honestly. I was like, his life is ruined, his life is messed up and he was young.

While Charlie does not expand on how "life is ruined" in this passage, some of the reasons these men described their lives as ruined revolved around the stereotypical expectations of what is required of men in our society: strength, friends, women, sports, and work.

Philly recalled:

> When I was in the hospital, I'm like, girls are done with. Basketball's done with. Everything that I knew was just done with. Everything that I've done I just can't do it no more. All that is memories now. So that's what I thought. I was like, alright, be ready to not be happy with those things anymore. And gotta do a whole new thing.

Based on the meaning that having a disability resulted in a ruined life meant that everything that Philly defined as central to his life, primarily women and sports, had to be forgotten. Needing to forget sports also meant that he needed for forget being a man, since sports are one way that men assert accepted masculine behaviors (Messner 2002). This also created the meaning that forgetting "everything" would result in being unhappy.

Forgetting "everything" could also mean forgetting friends, or being forgotten by them. Chris, who was on vacation when he dove into the pool, wondered how his friends and family would react to his injury during his inpatient stay by asking himself if his friends were still going to want him, and if his family was "gonna want to be around" him. Charlie, the man who thought life in a wheelchair was a "ruined life," repeats those concerns. When he woke up in the hospital after having both legs removed just below his hips, there were two thoughts that preoccupied his mind:

> My friends. I ain't goin' to have no more friends. My friends gonna just leave me. They gonna be like – 'aw man, you can't hang with us. You gonna slow us down…'

Slowing down his friends meant that his friends would reject him because he would not be able to keep up with them. The respondents acted upon the fear of rejection by finding ways to prove their normality. All the men in this study tried to preserve their presentation of self to their friends as a strategy to maintain friendships. Ethan, who was 22 at the time of his injury, tried to act the same:

> You know, when I was first hurt, I was like, oh, I gotta go show these people that, I'm, the last time they saw me, I was pretty…messed up…I just showed them that I'm still the same person I was before.

> You know…And they were just, wow, that's cool. Here you are, definitely the same cat. You haven't changed. You do the same silly shit. Well, yeah, that's me.

In order for his friends to see him as "the same," although he had clearly changed physically, he had to present himself as the "same cat." It was important to him, and other respondents, to create the image for others that they had not changed. By showing others that they were still the same people, they were modifying the meaning for others that disability equated to a ruined life.

Besides fearing rejection because of their disability, men also feared they would not be able to meet the gendered expectations in a relationship. Men addressed this fear by pushing away their wives and girlfriends. All of the men who were involved in a relationship with a woman at the time of their injury tried to end that relationship.

Charlie told his girlfriend at the time:

> 'You could leave. You could leave because you ain't gone wanna deal wit' a person like me and this situation. It's other guys out there, you know. Basically I'm tryin' to give her an easy way out at that time. And I'm like, you know, 'You don't wanna deal wit' nobody in a wheelchair. You never dealt wit' a person in a wheelchair before so you can leave' you know. 'Go.' But she didn't leave.

By telling her that she could leave to be with another man, he was saying that he would not be able to meet the expectations she should have for him as a man. On the surface, he asked her to leave for her benefit. Reading further into his request shows that had she followed through with his suggestion, she would prove to him that he could no longer be like "other guys."

A second reason for the men pushing girlfriends and wives away was to protect them from having their lives ruined as well. As David, involved in a car accident 10 years ago, says:

> Then you're at the point where you'd have the talk with your wife and tell her, 'You don't have to stay if you don't want to, you can do this, you can do that.' I guess everybody says that. You have to do that.

David was protecting his wife from what Goffman (1963) refers to as a "courtesy stigma," which is a stigma spread from the stigmatized person to people with whom he has close relationships. In David's mind, his wife could still have a fulfilling life if she left, but if she stayed, then disability would also ruin her life.

In an extreme case of trying to push people away to protect them from a ruined life, Allen, married for nearly 50 years, asked his wife to "let him go," implying a wish to end his life. One reason for that was that he did not want to be a burden on her. He recalls telling her this:

> I actually…I told [my wife] one time and that was the worst day. I told her, it, still hurts coming back. (interviewer: if you don't want to talk about it now, we don't have to.) It's alright. I told her, I said, look, this is no good. It's too hard for you, let me go. [crying as he speaks] I'll never forget the look on her face. And, that's when I realized that, you know, this was her decision as much as mine.

Wanting to end his life is an extreme example of trying to protect her identity from becoming stigmatized and allowing her to have a life that would not be "too hard."

Therefore, these men acted on the meaning of disability as a ruined life by pushing people away and maintaining the presentation of self as "the same." They also

found ways to modify the meaning. Modification of this meaning took place over time and through social interaction. Sometimes they needed to redefine what a “life” entails. Robert, who occasionally works as a motivational speaker, said:

> Hey, I can still enjoy life and I can still go to work. I can still have relationships; I can still be a vital part of society. I can still…do a lot of the things. I may not be able to do ten thousand things, but I might be able to do five thousand things. And five thousand things is still a lot.

Being able to modify the meaning of disability from losing it all, to thinking “five thousand things is still a lot” required work and effort. By focusing on things they could still accomplish, respondents fought against the ideas that others had about a limited life. Arriving at this new definition was a process that involved interaction with rehabilitation professionals and peer support groups.

Interactions with strangers also allowed for modification of meaning. Initially, these men thought they would no longer be able to date women and that they needed to push women away because they were not capable of meeting masculine expectations. The men in this study found ways to modify this meaning through social interaction. Being seen with a woman, a symbol of dating success for men, elevated their status among other men. For example, Taylor, a 32-year old, says:

> Sometimes guys sitting around may see me with a pretty girl and they’ll say, ‘I need to get me a chair.’ I tell them, it’s not that [the chair] man, it’s me, period. Some women they will say stuff like that too.

William had a similar experience:

> I was in the barbershop once with my girlfriend in Macon and it was kind of interesting. She went in with me. The other guy said, 'Who's that girl? That's your lady, man?' I said, 'Yeah, yeah.' Someone said, 'She's hot! Wow, dude! You're doing better than these guys that are walking!' I knew he was not being negative, but he probably never seen a man in a wheelchair with a woman who was really attractive.

Both of these excerpts show how these two men actively engage others in the process of creating meaning that changes the idea that men who use wheelchairs are not able to meet women, let alone date them.

Another way that these men tried to change perceptions about their lives was by being active around other people. Chris talks about how he tries to show others through his actions that he leads a fulfilling life:

> But do they see me in the mall, zinging around, with three or four bags in my lap? Just like they've got three or four bags in their [hand]. I think the best way for me to get my point across to somebody that doesn't know, is to get there and do it. For somebody to see me doing it, instead of moping around or feeling bad or being angry all the time. It's just not how I want somebody to remember me. Even if they remember me for being a dork, I was a dork who was doing something. I was out there living life, and I think that's the most important thing.

Chris knows he is an active agent in the development of these images and symbols that create meaning. It is important to him to show that having a disability does not equate to a ruined life, although many of these men initially identified this meaning as reality. Creating new meanings and images of success, happiness, and activity for these men was important for their sense of self. Had the men in this study shared similar experiences

before their injury, they might not have held on to the idea that disability resulted in a ruined life.

Summary

In this chapter, I explored the images and symbols that create meaning about disability, both for those who experience disability and for the people with whom they interact. I discussed three themes that emerged from the data: invisibility, hyper-visibility, and a ruined life. Most respondents had not consciously thought about disability or SCI before their injury. In more in-depth conversations, I found that they had preconceived notions about disability that influenced their early reactions to their injury. Through their own experiences and interactions with others, they modified the meanings and found ways to form a new understanding of what living with a disability means to them. These men were not very aware of disability before they were injured. The meanings they associated with paralysis were often negative and equated to a ruined life. Through the professional settings of rehabilitation and personal coping mechanisms, these respondents found ways to fight actively against the notion that their lives were ruined by demonstrating a positive presentation of self.

CHAPTER V: CONSTRUCTING MASCULINITY

Just as these men shared meanings about disability, they also shared meanings about masculinity. For them, in order to be masculine, or a man, they had to be physically and emotionally strong, economically responsible, sexually active, respected, and independent. This chapter explores how the respondents applied these meanings to their lives by examining the tactics and strategies they used to construct, or confirm, their masculinity. Primarily, the respondents actively engaged in impression management to construct a presentation of self that was congruent with masculine expectations.

I spoke at length with all respondents about what it meant to be a man. Because of the invisible and normative aspects of masculinity, 13 respondents had a difficult time generating a definition. After probing further, most respondents repeated the aspects of stereotypical masculinity as the basis for what it means to be a man. David, who is married with children, explains what it means to be a man in the following quote:

> …taking care of yourself financially. Being responsible for yourself financially, physically and everything else…And with a family, a man with a family you gotta be a man, be responsible for your family, make sure your family grows up and prospers and everything else. That's what family is – about taking care of your own, taking care of your business. That's what being a man is.

This quote highlights most of the qualities that my respondents valued as important to masculinity: physical and economic independence, providing for a family, and being responsible for self and family. The men in this study reconstructed their masculinity by

maintaining their independence, proving their strength, and portraying themselves as having normal bodily functions, primarily in relation to normal sexual function.

Independence

A key aspect to understanding American individualism is the idea of independence. Although we are all dependent on others for some things, the idea of the independent, self-made man is central to American ideology (Kimmel 1986; Rivas 2002). Within this study, men relied on their notions of independence as a means to construct masculinity. The most common strategy used to maintain independence was to reject assistance. Some respondents ended relationships because the person they were involved with wanted them to be "dependent." Robert, who was single at the time of our interview, offers the following example:

> Let's say from my last relationship I was in, and I think this friend of mine, this female, I think she wanted me to be so dependent on her, and I told her without getting upset – you know what, I don't know how this is going to sound to you when it comes out, but I don't need you for anything. I don't really need you to be my nurse. I don't need you to be my errand person. I'm with you because I choose to be with you, and if I do not choose to be with you, I won't be with you.

Pushing people away to regain independence was not limited to spouses and partners. Respondents also did it to their close family. For example, Philly describes how he dealt with his mother:

> I pushed my mother away, and let people know that I'm going to this life thing on my own. I don't need you. I'm glad you're there, and I appreciate the support, but I can't, I can't need you. I don't want to need you. I don't want to need you. So, I'm doing it, and I'm doing it,

> and I'm doing it alone. I was doing it alone before the accident. I can't let that change me now.

In these last two examples, Robert and Philly express a strong desire to be independent. They "can't" need help. Accepting help would deny them one of the most valued expressions of masculinity: independence. The presentation of self that both Robert and Philly offer is a completely independent self. By pushing people away who want to offer help, they are managing how others will see them. A difference between these two examples is that Robert defines his willingness to accept help as a choice, while Philly just rejects all help from his mother. Robert was concerned about his girlfriend's feelings; Philly was not. This is because of the expectations that our family will support us out of obligation, even if we do not welcome the support (Finch and Mason 1993).

A quarter of the respondents expressed that they would not accept assistance if they were trying to prove to themselves they could accomplish a goal. Bill, who contracted a viral infection that caused sudden paralysis at the age of 21, explains the concept:

> I think the only time that I resented anyone offering assistance was when I knew that it was a challenge, a personal challenge, and I wanted to face that.

These challenges included making it up a steep hill or lifting something heavy. For these men, their desire to complete a task served as a tool to demonstrate they could be independent when they needed to be. In this situation, Bill presents himself as

independent by the verbal and nonverbal indications that he does not need help, although he has to prove to himself that this presentation is real.

These men also engaged in body surveillance to ensure they maintained their independence. Levels of health-related surveillance varied from “little things” – drinking enough fluids to prevent urinary tract infections and paying attention to how hands were protected during sports to prevent blisters – to having a full mental checklist before participating in an activity that could cause serious injury. The respondents enacted surveillance to maintain acceptable levels of independence, a valued attribute for American men. Taylor, who lives alone and cares for his two-year-old son, explains why it is so important to “be careful” about making sure he does not hurt his arms:

> My arms are my arms and my legs, so I cannot allow them to get too sore or injure[d]…because if I do, then I won’t be able to move around…but at the same time, I have to keep them in shape…If you lose one of your arms and you still have your legs you can still get up and move around, but losing one of your arms when you don’t have your legs means you can’t do anything. Then you have to have a person to care for you as opposed to being independent.

Attending to the body was something these men did not have to do before their injury. According to Kelly and Field (1996), bodily injury can alter one’s self-concept and identity because the body is often taken for granted. After injury, the body ceases to be taken for granted as part of one’s identity. The new reality these men construct is that their self-concept must shift to include their bodies in order to maintain independence.

By comparing their level of need to other people with disabilities, they confirmed their own independence, therefore confirming their masculinity. Taylor, who lives alone, offers an example of how this comparison takes place:

> Some people will let people do it [push the wheelchair] for them, being lazy. But I won't let them do it. When people try to push for me I tell them, "I got it." I feel if I let you push me, and you just continue to push me when you're not there, who's going to push me? If I need help or I'm tired, I'll allow it, but I won't allow it otherwise. I feel like that's being lazy. There are going to be situations where there is no one available to help you, so you have to do it on your own anyway.

Using the example of allowing someone to push his wheelchair, he sets up a dichotomy between those who allow help as lazy and those who do not as independent.

Taylor's comparison of himself as not lazy to those who need help as lazy stands in contrast to Kirk's comparison of himself as independent and those who might have higher levels of impairment. As he says:

> 'Cause sometimes, maybe I don't need help, but maybe one of my fellow SCI people who, or some other disabled individual who would need the help, and I'm glad to see people who are willing to help. To me, I don't need the help, I find it more annoying than the nice little lady who tried to help me and then slammed my fingers in the car door. Or the people who try to help me by holding open a door, but stand in the doorway so I can't get in anyway.

Kirk is a paraplegic and he is placing himself in contrast to those who might require more help. In contrast to Philly's narrative that accepting help is bad for all people, Kirk feels that it is acceptable to receive help when it is needed.

Building on Kirk's understanding that some people will need help, another strategy that some of these men used to maintain their independence was to pay for the help. Chris, who requires assistance with personal care, says:

> I still feel like anything's possible. I can do whatever I want to set my mind to. Do I do it myself? Or I hire somebody else to do it, or coordinate a group of people to do it. I can be every bit of a man anybody could ask for.

Hiring an outsider to assist does not eliminate the assertion that he is independent. He considers himself independent, as all but three of my respondents did. However, the way that he modifies the meaning of independence to include receiving help keeps his self-presentation of masculinity intact because he remains in control of what gets done and how it is accomplished. Economic and social resources varied for my respondents and having the resources available to hire help can offer a more positive self-presentation of masculinity, since appearances of independence remain intact.

The Normative Body

Another concept that emerged from the data was the need to present others with a normal-functioning body. In Goffman's (1963) analysis of Stigma, he notes that a stigmatized individual's social and personal identities can be significantly altered by disclosing information. Relationships are also altered by the level and type of disclosure that takes place (Isaksson, Skar, and Lexell 2005). Less than half of the men in this study disclosed information to friends or sexual partners about bodily impairment beyond the visible paralysis. These men wanted to limit their friends' and sexual partners' awareness

about sexual function more than any other type of bodily malfunctions. By disclosing information to some people and not to others, these men divided their social relationships into the "knowing and unknowing" (Goffman 1963:3). This serves as a specific type of impression management. Drawing boundaries between those who "know" and those who do not was a primary way for the respondents to manage their stigmatized identity.

One way these men constructed their masculinity was by seeing themselves as having normal sexual desires, even when their body did not function in "normal" ways. Robert, who is able to get an erection without the use of drugs, unlike most men with SCI, says:

> I think being a man, every man want to be able to please his woman. And, to me, I'm still a man, and I've still got needs. Well, needs in a sense where, of course, I'm a man, I'm going to get horny. Just because I'm in a wheelchair, that doesn't stop my sex drive.

Robert separates the psychological aspects of sexuality, his sex drive, from the physical aspects of his disability. By asserting that he is still a man because he still has sexual desire, he constructs masculinity to mean that sex drive, rather than sexual performance, is an indicator of how well he is able to meet his own expectations of being a man.

Before Robert was aware that he could have and maintain an erection, he was concerned about his sexual ability. The fear that he could not get an erection occupied his thoughts for five weeks until a nurse noticed he was erect:

> I think only men can relate to this. And I can get an erection. During that time [in rehab], I didn't know I could get an erection…until like, five weeks later. But during that five weeks I was worrying about that. Wondering…so when I got over to rehab, and I'm lying in bed,

> closing myself off from the world, and the nurse came in, pulled the covers back, and she's laughing. So, I'm laying on my back, and I'm like, 'whatcha laughing about? What's wrong?' She said, 'I'm laughing at you.' I said 'Well, why you laughing at me?' - she's like, 'you're erect.' And mind you, I've got my eyes closed, and she's like, 'you're erect' and I'm like, 'what?!' I'm like, 'roll the bed up, roll the bed up.' So she rolled the bed up and I just looked at it, and I just looked at it, for about 30 minutes. And you know what I said? (what?) I think I'm gonna be alright. I mean, for a man to get an erection with his masculinity and his manhood. This is his manhood.

Robert equates his masculinity with the ability to get an erection. But getting an erection is more than the physical result. An erect penis is the ultimate symbol of everything masculine – the penis "stands in for and up for the man" (Potts 2000:85). Robert spent 30 minutes staring at his erect penis, which gave him a glimmer of hope that he was "gonna be alright."

The association of masculinity with sexual performance can create anxiety for those whose erections do not appear "normal" (Grace, Potts, Gavey, and Vares 2006). Since SCI results in the decreased ability to achieve and maintain an erection without the use of drugs or pumps, most men felt the need to present a reality that they could still perform in order to alleviate some of this anxiety. One way to construct this reality was to allow others to assume that things were "normal." In the following quote, Philly offers an example of how this interaction occurs:

> I try to keep it [decreased sexual function] a secret. It's more of a secret now than anything. Like, my boys, they think that, they know nothing about me. What they know is whatever I tell them. And, it's pretty much, everything is just normal. And it's not. But I let them know it is. And that's what they believe and that's what they're going to have to. And we know, we know it's different, but nobody else

> knows. All the girls that know me, they think that it's normal just like anybody else. Even if I never get with any of them, it does me and my heart right to know that they think I'm normal. And that's the whole point. And that's what I want. That's what I try to maintain.

Not sharing that things are "different" is a way to maintain the masculine front. By having "normal" sexual function, Philly's masculinity remains intact. By keeping others in a position of "unknowing," the stigmatized identity of limited sexual performance is never made public.

Sexuality for men is seen as something that is natural and uncontrollable. It is ruled by sexual urges and the actions of the penis, which is often referred to as a separate entity (Potts 2001). The "uncontrollable penis" is viewed as a symbol of virility and potency for men when it is erect and as a loss of masculinity when it does not function under the direction of the man (Grace, Potts, Gavey, and Vares 2006). Viagra offers a solution to this perceived loss by medically correcting the lost erection, and the anxiety that goes along with it, and gives the man control over his penis.

A strategy used by these men to keep others in a position of "unknowing" was the use of Viagra and other drugs for erectile dysfunction. As one respondent said, "we got Viagra now." In order to maintain the presentation of self as normal, these men strategize when and how to take Viagra so that their partners would not know they had assistance in achieving and maintaining an erection. Chris, who is single, describes how this takes place:

> I begin to plan a little bit with the medication. I don't have to have it every time, but it's a lot better if I do, gives me a little bit of help.

> And, um, sometimes I tell her that I'm going to the bathroom and take a pill and drain my bladder before we get down and dirty, but usually I don't.

Chris does not need Viagra because he is able to become partially erect, but it isn't "normal" or "as good." Viagra ensures that his presentation will be as a successfully potent male. Taking Viagra in private allows him to achieve this presentation without his sexual partner "knowing" he had some help.

In addition to hiding information about sexual function, these men chose not to share information about other aspects of bodily failure, like bladder and bowel incontinence. People who have problems with incontinence are viewed as less able, less competent, less attractive, and less desirable as companions (Mitteness and Barker 2000). In order to avoid these labels, these men would keep a potential partner from "knowing" what steps were needed to empty the bladder and bowel. This often resulted in men giving up on dating or spontaneous parts of their lives. Like planning when to take Viagra to appear sexually normal, these men would plan to perform bodily maintenance to appear able. Kirk, who no longer dates because of the "hassle involved" in not disclosing his incontinence, provides an example:

> A lot of the spontaneity of relationships is gone. There's a lot more planning that has to be involved…and to explain to them [women] why things have to be a certain way, like…it's kind of difficult to explain to a woman you're just meeting that, okay, we have to go out at seven, because I have to be home by eleven, because I have something I have to do every night at a certain hour…but, you don't want to go into it, because, I can say to you because we're in a professional setting right now, but to describe the program to a complete stranger. Kind of difficult. Not the best of starting a

> relationship…it's kind of hard to go into a relationship, yeah, well…the way I have to empty my bowels, I got to shove a finger up my ass and twist it around a few times, and I thought getting fingers stuck in my ass before the injury was supposed to be a sexual turn-on, now it's just maintenance.

Because of my relationship with these men as a "professional" researcher and not as a potential partner, I am included among the "knowing," but sharing this with another woman might ruin the relationship. Identifying with his malfunctioning body as a source of maintenance and not a source of sexual pleasure prohibits Kirk from engaging in romantic and sexual relationships.

The men used the strategy of avoiding dating and sexual relationships as a way to keep women from "knowing" that they had problems getting an erection, and therefore could not sexually "perform." For example, William was "very nervous" before he started dating after his injury. When I asked him what things he was most nervous about, he replied:

> Sex, at that time. Performance. What was going to be the situation for me? Sometimes you didn't want to get into situations. Sometimes I held back in dating.

The "situation" for William was whether he could get an erection. He did not want to go on dates, meet women, and potentially have his masculinity questioned if he could not "perform."

For a quarter of the men in this study, having an erection was not the only aspect to their masculine sexual self. Sexual performance that resulted in pleasure for the

woman was central to how these men viewed sex. Larry, who has avoided dating because of his fears of sexual performance, provides the following example:

> Well, I can't be on top, but I like to be able to move my body too, you know, work with her, you know what I'm saying, and I mean not being able to do that. It's just a guy thing I guess. I don't know. I just don't feel right, the woman is doing all the work and I'm not able to do nothing. I feel like she ain't get what she want, you know what I'm saying?

Respondents who were married did not have to worry about pleasing a new partner, but they did still express concern about pleasing their current partner. Gary, who married his childhood sweetheart later in life, describes how his inability to be an active participant when having sex with his wife limits both of their pleasure:

> Well, I've tried Levitra. It works. Same with Viagra. Those all work. But I'm just laying there, so [my wife] has to do everything, and uh, I wouldn't, I wouldn't have any sensation of an orgasm or anything else. So my pleasure would be zippity-do-da [nothing], and for her, it would be all the work, the times that we have tried it, it's her having to do all the work which means she's not getting any satisfaction out of it either. We can cuddle. But she's gotta get the lift, put me in bed, roll me over. And that is work.

Having bodies that functioned as whole moving objects was just as important as knowing they were able to achieve an erection. When the whole body did not work in a way that allowed them to fill the normative heterosexual constructions of masculinity (Butler 1993), they feared that their partner would not "get what she wanted." Single men who felt a need to conform to these ideals did not pursue relationships because of the fear involved, while married men stopped desiring sex because of the lack of pleasure for both partners.

Twelve men described viewing sex differently than the normative heterosexual performance. The primary way they constructed a new sexual performance was by being more creative and communicative with their partners. Creativity and communication provide an opportunity to vary from the "restrictive notions of manhood," because within the "restrictive" sense of masculinity, communication is not considered acceptable (Tepper 1999:37). Ethan offers an example:

> I mean, before, when you feel everything, you feel everything. You already know what's going on. So, and there's more signs [physically]. But now, without being able to feel…70 percent of my body, you have to communicate a little bit more. And, like I say, that's the interesting thing that you find out about your body and about yourself that you can transmit and transcend the, the whole penis issue. And get a really good rush out of it. For not being able to release yourself or whatever, it's like. But 11 years is quite a long time to not have, you know, that release…had that release, but just in a totally different way…which is good.

Communication with a partner can lead to a more pleasurable experience for the man and woman. Ethan, and other respondents, have found that by communicating about feeling and stimulation, they can "transcend the whole penis issue." Four respondents in this study had the ability to reach a "normal[7]" orgasm. The remaining respondents described "missing" that feeling and response. However, many had found ways to communicate with their partners what was stimulating in a way that could produce a "release."

While Ethan sees communication as the primary way to "transcend the whole penis issue," David includes "substitutes":

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[7] "Normal" orgasm was a term used by one respondent to describe an orgasm that resulted from direct stimulation of the penis and resulted in ejaculation.

> Uh, let's see, there's the substitute for a penis. There are toys, there's oral sex. There's more touching and compassion. It ain't just wham, bam, thank you ma'am.

By substituting for the penis, David remains within the normative heterosexual act of penetration. However, he deconstructs the normative expectations by including more feminized acts of "touching and compassion."

Typical notions of masculinity were also modified when the respondents needed to disclose information about bladder and bowel incontinence. Four men in this study challenged expectations of communication about by creating social relationships where the other person was included among the "knowing." Family members were automatically included among the "knowing," as well as some close friends. However, not all those who "knew" were permitted to "know" everything. Robert, who has a number of family members who live near him, explains that he was able to ask for help from one male friend, including assistance with urinary bags and helping him into bed. He would not allow his male friend to help with other activities:

> [My friend] knew how to put me in bed and change the leg bag back to the night bag. Get into my bag and stuff like that. But as far as other personal care like washing, I would not allow them to do. But, my brothers, they know about that.

Robert creates a division from the "knowing and unknowing" by dividing the types of tasks he allows others to assist him with. Feeling comfortable with allowing family members to assist with washing stems in part from a sense of family obligation (Finch and Mason 1993; Tepper 1999:37), as well as his need to separate a male friend from an

act that could be viewed by others as intimate. In our discussion, he explained that he would allow a female to assist with bathing, because "men and women are supposed to share that [showering together]." By constructing showering as a sexual act, Robert would allow a woman to help him, but not an unrelated male.

In two cases, sharing had to occur because of a bowel or bladder accident. Brendan recalls a specific exchange with a friend after he had an accident:

> I said to [my friend] 'I'm running to the back of your truck.' He was like, 'What are you talking about?' I was like, 'I gotta run to the back of your truck because I doodied on myself.' And I was so worried to tell him, but he told me, 'You can't help it. You're still my boy!' That was the best thing, and I thought that was awesome.

Including his friend among the knowing was out of necessity. As Goffman (1963) states, managing information regarding a stigma generates anxiety when confronted with the need to disclose information. Brendan was worried that his social identity would be disrupted by this act of disclosure, but those fears did not materialize, which allowed him to maintain his sense of self.

Emotional Strength

A third theme that related to the construction of masculinity was the ability to stay "mentally strong," or not to show emotional weakness. Staying strong emotionally allowed these men to meet the stereotypical norm that "boys don't cry." Fifteen respondents expressed the need to "stay strong" emotionally in order to "make it." Previous research examines the gendered differences in emotional expression, and researchers have found that through the socialization process, males learn how to express

emotion and feeling, as well as how to act when faced with emotional experiences (Lister 1991). Pleck and Sawyer (1974) stated:

> Staying cool, no matter what, was part of what we learned growing up male. We knew that big boys didn't cry, and that real men didn't get too excited except in places like football games. Spontaneous emotion – positive or negative – was suppressed or restricted to certain settings. We learned to mute our joy, repress our tenderness, control our anger, hide our fear (p.4, cited in Lister 1991:225)

Thoits (1995) attributes the pervasiveness of the dominant male values in our society, such as independence and physical strength, as reasons for the inexpressive, stoic style men exhibit when dealing with stressors.

These men saw the need to stay strong as a sense of personal responsibility. Robert offers this perspective, which elaborates on the active nature of this strategy:

> As far as being in the chair, just the mental aspects of relaxing yourself and saying to yourself, you know, I gotta stay strong mentally, and not let the negative thoughts come on in. Because when you start letting negative thoughts come in your head, you become so negative about the situation, and the negative energy, and you be stressed out, you stress yourself out, you don't want to do anything.

Since these men no longer met the criteria of being physically strong, they actively constructed an image that they were mentally strong. By actively constructing the reality that they were mentally strong, they were still able to contribute to society by doing something rather than nothing.

Staying strong emotionally and mentally was also performed to show familial responsibility. The concept of familial responsibility was prevalent for all the men who were married or had children living at home at the time of their injury. Anthony, a father

of four, elaborates on the concept of mental strength as responsibility in the following excerpt:

> Once they started teaching me about my disability and telling me, you know, that I could live with my disabilities, and so I had to get it in my mind, well, I gotta do what I gotta do and life goes on. You know. ‘Cause you know I had four young kids at home at the time and…‘cause like I said, even though you’re paralyzed, you still got a life. You still gotta live.

Both Robert and Anthony describe the need to keep going. Overcoming negative thoughts and maintaining responsibility for a family are both aspects of a “disciplined self” (Lamont 2000). Mental strength equals responsibility. Through responsibility, a central construction of American masculinity, these men assert control over aspects of their lives that appear uncontrollable (Lamont 2000).

How these men construct the idea of the “disciplined self” is in opposition to those who are not as “mentally strong.” They construct this reality by comparing themselves to those who show weakness. Anthony offers this example:

> It’s tough, you know. And if you have a good mindset then you’re gonna survive it. Like I say, I’ve dealt with different people and I’ve seen the different attitudes, and sometimes you could just about tell who is gonna make it through the year and who ain’t. And I try to tell ‘em, I say your attitude is key and you gotta have…a good attitude to make it through it. And if you bitter, you angry and all that stuff, that don’t really help you. You have to push that stuff to the side.

When these men push their emotions to the side, they continue to construct masculinity as stoic and emotionless (Pleck and Sawyer 1974). Whether or not these men always did

push these emotions to the side, the need to express that they were able to do it was central to the self-presentation they offered during the interviews.

The men in this study also maintained their mental strength by comparing themselves to people without disabilities. Mike, a 28-year old quadriplegic injured in a work-related fall, explains how he is stronger than other people are:

> My grandmother has made the comment 'if I can change places with you, I would.' But it's like I told her, I wouldn't even let that happen because in a way I'm glad, I mean, I'm not glad, but I'm glad this injury happened to me instead of some of my family members or my friend, because I don't think they would have took it as well. They might have given up; they'd maybe give up and just die.

Mike sets himself apart from other people who are not injured because he thinks he is better equipped to handle the challenges of his injury. He has proven his mental strength by staying alive while others might allow themselves to die.

Suicide and death are possibilities for men who do not meet the expectations of masculinity. Bobby, a quadriplegic, offers the following:

> If I dwelled on [all the bad things], I'd go ahead and blow my brains out, get it over with. Ain't no sense in it.

Bobby and Mike both indicate that mental strength is necessary in order to prevent suicide. Mental strength is needed to meet the social expectations of masculinity. Failing to meet these expectations meant that life was not worth living, reinforcing the meaning that having a disability meant that life was ruined.

There were times that these men were not able to maintain their self-presentation as emotionally strong and controlled. Given how crying and emotional expression is not

sanctioned for men, it is understandable that there would also be a level of fear associated with such expressions. The three men who cried in this study expressed feeling uncomfortable with having done so. Philly, who presented himself as extremely independent, describes the following experience when he cried during his time in the hospital:

> I was in the hospital like three or four months after [my injury]. And, I just…I just cried. I remember crying…You know, I hate crying. Like, a lot. I hate to see other people cry, I hate it so much. I can't believe I, I remember I was in my bed, and my grandfather's in there with me, he's the only one that seen it. I wouldn't let anybody else see it. And I just broke down.

Like the strategies these men used to maintain boundaries between the "knowing and unknowing" in regards to their bodily functions, Philly only allows his grandfather to witness his emotional weakness. Crying, a visible symbol of weakness, threatens the masculine self-presentation of emotional strength. Crying is seen as an indication that a man is weak, lacks courage and manliness (Gray, Fitch, Fergus, Mykhalovskiy, and Church 2002).

Summary

For the men in this study, the creation and modification of masculinity was an active process, which involved constant awareness that others were observing their presentation. Men created and performed normative masculinity by focusing on the extreme expectations of manhood: absolute independence, a normative body – especially an erect penis – and extreme stoicism. One way to protect self-presentation in regard to

body management and emotional strength was to maintain a boundary between the "knowing and unknowing." Men modified their ideas of masculinity to include allowing help when necessary and communicating about sensation and pleasure during sex. In this study, men did not allow emotional weakness; therefore, they did not modify their meaning of masculine as stoic after their injury.

CHAPTER VI: LOSING MASCULINITY

> *"Guys have often asked my girlfriend, 'Why are you with him, he can't do anything for you? He ain't nothing but half a man.' – Charlie*

> *"I guess I'm not supposed to be a man anymore, just because I'm paralyzed…I guess I'm not a man anymore." – Bobby*

In the previous chapter, I discussed the strategies and tactics men used to reconstruct normative views of masculinity. In this chapter, I explore the connections of the individuals and their larger social worlds. I examine how the respondent's goals of masculine performance are situated in structural contexts, which restrict their opportunities "to be men." This chapter examines the way these respondents negotiated identities and roles through a "negotiated order approach" (Strauss 1978). I specifically analyze the structural contexts of space, employment, and marriage as places of negotiation.

Space

Examining the built environment, which I will explore here, allows us to study the connections between the individual with a disability and the larger society. In the previous chapter, I examined how independence is one of the ways the men in this study construct masculinity. The built environment renders these same men dependent (Oliver 1993) and limits their social interactions (Hastings and Thomas 2005). Environments that are built with wheelchair users in mind, like rehabilitation hospitals, encourage independence. However, many respondents reported returning home to find that the

independence they had found in the rehabilitation hospitals was lost because of structural barriers. Philly, who has relocated to an accessible condo in Atlanta, recalled the following about his Mother's house, where he spent time after rehab:

> When I go home to my mom's, and you know, she has two big steps in the front door, five or six steps…from the living room to the bedrooms, six steps from the kitchen going downstairs to the den, so it's nothing but steps. I hate my [mom's] house now. I don't want to go back, the bathroom's so small, I can't even turn [around] in there…for me when I gotta pee, [I have] to go in the bedroom. I need two people to help me go up the steps…and now I need [them] to get back downstairs, and I need [them] to get out front.

This excerpt offers an example of how living space can require total dependence on others for entry, exit, and all movement within the house, including bathroom use.

No current legislation requires accessible design for private homes, and as a result, these men repeatedly recount situations where they had to choose between being dependent on others to access space or avoiding social functions such as birthday parties, going-away parties, holiday gatherings, or even a simple dinner because of the structural barrier. Chris described an incident that many would see as just an architectural barrier, but for him it was more emotional because of the connection he lost with this friend:

> One of my friends had a going-away party, and she lived on the third floor of an apartment complex. And that was where she decided to have her going away party. I didn't want to be carried up three flights of steps. So that was a physical barrier, [and] it was emotionally difficult for me.

Chris' goal was to join his friends at a party, and the built environment is the structural property that determines the outcome of this negotiation within the negotiation context. He chose not to attend the party in order to maintain his identity as an independent man.

Within this context, Chris recognized that the inaccessibility of this location was not chosen in order to purposefully discount his desire to attend the event. Rather, when social events are planned in private homes, the reality is that most people take for granted the accessibility of space. Even two steps can be limiting to a person who does not want to place their safety in other people's hands, or whose mobility impairments require that they use a wheelchair that cannot be lifted.

Friends and strangers are often helpful when a person with mobility impairments encounters architectural barriers and is willing to accept the help. For many, allowing others to lift or carry them in their chair is often seen as an attack on the independence they have gained over the years. Ethan, who travels frequently, recalled the following about a recent trip to New York City:

> I get out there [to the city] and there's a step or two up or down into every building. The doors are about eighteen inches wide. I ended up pissing out in the street. And I was just, I was angry. I was just like, this really makes me feel, you know, handicapped…I think I got more angry because now I'm so independent. That it just takes all that you've worked for and puts it to naught. 'Cause then you gotta get lifted up into a place.

Unlike Chris, Ethan negotiated his dependence differently by sacrificing his identity as an independent man in order to participate in the social experience of being in New York City with his friends.

Spatial contexts are not limited to stairs and narrow doors in private homes. The respondents faced barriers to interactions because of the social construction of conversations. Gary offers:

> [At parties] everybody's standing and I'm down here. Now if they sit down, everybody sits down, then I can have a conversation. But that's not how conversations go. Conversations migrate around the house, and I'm stuck in one place.

The idea that "conversations go" a certain way highlights the social construction of conversations. People have created spaces that encourage mingling conversations as opposed to sitting, and have interpreted these events as a natural fact of conversations. The way spaces encourage this action is invisible. Mingling at a party is normative, while sitting, unless with a small crowd, is not. This normative construction of how "conversations go" can cause discomfort and isolation.

Bars and other public places are constructed to facilitate normative conversations. Bars have high-top tables and tall chairs so that a seated person can still be close to eye level with those who are standing when the space fills. These settings are so normative that they are invisible to most people. Seeking to change the situation for the respondents to make them more comfortable caused "too much trouble." They opted not to attend events that were not going to be comfortable.

There are times when store owners try to accommodate their patrons, but in the process, they create a visible difference between customers who use wheelchairs and those who no not. Chris recalled visiting a local restaurant that used to have a sidewalk

path that allowed him to enter and leave without assistance. On a recent visit, he found that the owners installed a lift that required assistance to operate. He says:

> They had a little path, ramp, that went around the tree to get upstairs…but now they have…one of those elevators. Like a lifting platform, and where before I could push up the ramp and nobody'd even take a second look, now I've got to stop the concierge or hostess and ask them to get the wheelchair lift down and everybody stops…eating so they can watch the wheelchair go up the elevator. And it just feels very out of place.

Where Chris could previously enter the restaurant in a manner that did not draw attention to himself, he now draws excess attention. The meaning of this interaction for Chris is that he is now hyper-visible. The visibility created by this modification exists in contrast to the invisibility of spatial barriers.

The invisibility of the barriers are due, in part, to the way the built environment is "intrinsically linked to issues of power" (Dovey 1999:6). The environment is built by those in power for the majority of users, leaving those with mobility restrictions out of the process. Respondents expressed that because they do not often have the power to change a public space, it is not worth the time or effort to work around a barrier. Rather than trying to get something done they will "take their money elsewhere." None of my respondents have reported a business for failing to meet ADA regulations, in part because of the frustrations involved in reporting non-compliance and the vagueness of the law itself. Miles, who was injured four years ago, explained:

> Well, they say 'reasonable accommodation,' and I don't really know what they mean by that. Reasonable to whom? To them, who are making all this money, or to me, who wants to use a bathroom?

The way space is constructed has left him with a feeling of powerlessness over even the most basic needs, such as using the bathroom. On an individual level, many men report feeling powerless; however as a group, men have more power in our society (Kimmel 1986). Feeling powerless about change was a common response among this sample.

The vague language associated with the ADA allows businesses to interpret the law in various ways, often in their favor (Schwochau and Blanck 2003). Following the letter of the law, but not the spirit, is common among business owners. The small changes to make a bathroom truly accessible, such as adding lever door handles and lowering paper towel dispensers, are not within the visible scope of access. Having a bathroom that is large enough for a wheelchair to turn is required by law, but the law does not forbid items from being placed in the path leading to the bathroom. How the law is interpreted by business owners and customers affects how assertive individuals are in trying to ensure enforcement.

Employment

The ADA prohibits employment discrimination as well. However, 15 respondents felt like they were denied employment solely because of their disabled status. When discussing poverty, unemployment, and homelessness with undergraduate students, it is common to hear a statement similar to the following: “I don’t understand why homeless people don’t just get a job. It isn’t like they are disabled or anything.” This is a powerful and problematic statement on many levels, two of which are worth discussing here. First, the students are clearly blaming the poor for their position in society, as opposed to

examining the larger structural inequalities (presumably, the instructor would provide an answer to this question). Second, the statement implies that having a disability equals inability to perform work and that having a disability takes away the desire to work. Research has shown that over 65 percent of working-age adults with disabilities would like to work, yet are limited in finding employment that is suitable (www.nod.org).

Respondents in this study did not understand why the system of employment is so "messed up." Robert, who has a college degree and occasionally works as a motivational speaker, offers the following:

> One thing I realize being in the chair is that everybody I talk to wants to work. I don't know anybody that don't want to work. They want to be able to control their financial destiny. It is so messed up. The limitations they put upon people who are trying to work who's disabled. You've got somebody that wants to work, let them work. Let them work.

Taylor, who has a high school diploma and is unemployed, adds to Robert's thoughts with some possible explanations for the denied opportunities:

> The biggest challenge was getting the job, because being in the chair was such an issue. The requirements were: 'You have to be able to carry boxes up and down the stairs, be able to lift 50 pounds' A lot of the jobs that [companies] had available didn't even require that, it was just something they said to keep from hiring. Some companies will say stuff like that, mainly because they say their insurance will go up. So to keep their insurance from going up, they won't hire you.

Constructing the requirements of a job to fit the normative able-bodied person immediately prohibits most people with disabilities from getting the job, and it protects the employer from any form of hiring discrimination charges, since the applicant with a

disability would not be “able” to fill the requirements of the job. When companies do this, it denies men with disabilities the opportunity to be in “control of their financial destiny,” which is a requisite for being a man in our society. We live in a society that is built on the protestant work ethic that rewards those who are industrious and self-sufficient (Lamont 2000) and we equate paid work with social status, especially for men (Hayden 2002; Kimmel 1986). By equating paid work with status, we marginalize those who are denied employment opportunities (Barnes and Mercer 2005).

Having to negotiate their identities as men within the structural boundaries of ability-based employment was a difficult challenge for the respondents. To them, work meant more than just getting a paycheck. Having a job meant financial control, but it also meant status, freedom, independence, and social validation. Being a paid worker was a role that was strongly tied to their masculine identity.

We marginalize unpaid labor in our society. Most of the research about informal and unpaid work comes from feminist research (Barnes and Mercer 2005) and examines the separation of public and private spaces for men and women. This bifurcation of space results in the marginalization of “women’s work” and the reinforcement of gender segregation of the workplace (Hayden 2002). For men with disabilities who cannot find paid employment often find themselves in this space. Volunteering is one way the respondents fill their time and participate in social spaces. As Gary says: “I can only do volunteer work…as far as actually makin’ money at anything, there’s nothing I can do to make money.” Brendan also volunteers at the rehabilitation hospital. He would rather

work, but “out of necessity” (Taylor 2004) he found alternative ways to spend time in spaces:

> I want to have a job because I like meeting new people. It’s something to do. Right now, I volunteer at [the hospital] to pass the time. I’m taking acting classes. I need something to pass the time.”

Volunteering is not a salient identity for these men. Volunteering is something they do, not something they are. They use volunteering as a way to “pass the time” until something else materializes that can provide them with an identity they can use to support their masculine role.

Loss of employment or the inability to secure employment may also decrease levels of social interaction for people with disabilities (Fong, Finlayson, and Peacock 2006). Similar to men who feel their status is marginalized because they are not part of the paid work force, many respondents feel socially isolated because they do not have a shared experience with others who do participate in paid work. They do not have the same social roles and find it hard to converse. Brendan thinks social connections through volunteering could be beneficial; however, he feels insecure about these connections because he is “just a volunteer.” Because of this, he feels that he can not participate on a social level with the people he meets. As he says:

> When I meet people who work at [the hospital], they are like really smart people and when we talk, I feel like I don’t have anything to bring to the table. They would talk about what they did that day and their jobs and stuff like that, and its like, “I don’t have a job, I volunteer.”

Ethan echoes Brendan's statement. Ethan does not work but receives full military benefits. Among the respondents who were service-connected veterans, most were not interested in finding work, primarily because they receive what they consider to be sufficient pay. One aspect that Ethan does miss out on, however, is the social interaction. He says:

> But, you know, there's been times that I feel like I'm missing out, almost, because I don't have a job. At least, a job, you meet people and you, you know, you socialize and you do things. I socialize. I have a lot of friends and I do a lot of stuff. But doing that at a job would be just like, you know, go out to happy hour with the, all the guys and girls from work. And I just don't do that…it's just a little bit different not having a job. 'Cause it's a weird, um, existence because it is ultimate freedom, but it also puts a lot more stress on your ability to make, to make conversation, and to make, 'cause you know, it's not like, 'Oh, what did you do at work today?' 'Oh, nothin'.'

Within both of these interactions, or the desire for interaction, these respondents are concerned about their presentation of self as responsible, hard-working men. There is an underlying moral obligation to the presentation of self in that the person is supposed to live up to the "rights and responsibilities" of an identity, and others are supposed to respect that identity (LaRossa and Retizes 1993:149). These men want to be men and to be identified as such. Within the social interactions described above, their identity as men might be questioned because they are not participating in the paid workforce.

This underlying moral obligation, and the potential questioning, keeps some men from dating. As Brendan says:

> I haven't really dated in six months. It's like I'm nervous to talk to girls now because I don't have anything to bring to the table. What girl is gonna want to date a guy that's not working?

Brendan spends nearly 30 hours a week at the hospital working with new patients, but because volunteering is not an identity related to his desired role as a worker, he discounts any of the similarities between the two. This is primarily because the role as provider (Lamont 2000) is missing from the context.

Being a provider could mean taking care of a family, or one's own financial needs. Bobby, who lives with his father, stated:

> I gotta get a job, start making some kind of money on my own. So I can get out of my dad's house…I don't really feel like one [a man] cause I can't go out and do the things that need [doing], and that I want to do.

Not meeting the expectations of financial independence - living independently from parents and taking care of things that either need to be done or that one wants to do – creates a feeling of emasculation. Bobby does not feel like a man because of the way masculinity is constructed to focus on independence.

The only place where black and white men created different narratives about their experiences was in relation to employment. Both groups felt they were denied employment because of their disability and they were both equally represented in the analysis of the meanings of work. Two narratives emerged from the black men in the study that were not present in the responses from the white men. First, black men talked about "quotas" as a reason they do not want a job. Second, black men saw disability as a

leveling process that erased color. The white men did not express an interest in discussing how their race has privileged them or how they were now eligible for Equal Opportunity Employment that would not have been offered to them before their injury. The overall story was the same though; the black and white respondents felt restrained in a structural context of ability.

As an example of how the black men applied the meaning of quota to employment, Robert offers the following:

> ‘Cause I think…being a man, you want to be respected as being a man. You don’t want to be, I don’t never want to be given a job as quota. Because I’m black. I want to be given a job because I’m a man and I have the credentials and the skills and the knowledge to perform that job task. I don’t want to be given a job for pity, because I’m disabled.

Two things are worth highlighting in this excerpt. Robert parallels his race with a quota system, a common misconception of Affirmative Action policies. His identity as a disabled man results in pity. He has made a clear separation between the two: racial minorities get jobs because employers have to fill a spot on a spreadsheet, while people with disabilities get jobs because employers feel bad for them. Conversely, (white, able-bodied) men can just get a job just because of who they are.

Six of the black respondents also bought into the ideology that we live in a “color-blind” society, and that race was not a factor that affected their employment status. Racial inequality is not eliminated in a color-blind society; rather it is not acceptable to talk about inequality based on race. Within the discourse of color-blindness, inequalities are

not explained by examining structural factors. Any inequalities that persist are the result of a person's individual shortcomings or the failure of a community (Doane 2003). Within this context, these men saw their social position as "disabled" as the failure that resulted in inequality for all members of that community. The following statement by Taylor is an example of how he thinks disability is the primary limiting factor in employment, and not race:

> When I was walking during high school, it wasn't a problem for me to get a job. All through high school I had a job. Mainly it's because of the chair [that I can't get a job]. It's not only with me; some of my teammates that are white, it's hard for them too.

William, a black professional, explains about the lack of employment for black men:

> There are certain things, particularly with African Americans, that are used to emasculate you: economics, social opportunities, and various things hit African American men disproportionately. One is not able to choose his destiny, or do what they want to do, nor [do they] have the proper access to do these things. Economically, you are not able to take care of yourself and/or your family. Being disabled on top of that can be an emasculating experience in this society.

These narratives show a very different story than what one might expect if engaged in a conversation with the undergraduate students mentioned earlier. The experiences of these men in finding employment give life to the two-thirds of working-age adults with disabilities that want to work, yet are denied the opportunity to do so. For these men, and many others, work is about so much more than a paycheck; it is about fulfilling the expectations of being a man. The black respondents used a color-blind narrative to

explain why disability is more limiting than race when it comes to employment. However, they recognize that being black adds another marginalized identity that could hinder their ability to meet the expectations of manhood.

Marriage

A third context that these men had to negotiate in regards to their masculine identity was marriage. The men whose wives served as a primary caregiver had to negotiate independence with their identity as a caring husband. While there is much written about the stress that a caregiver experiences and the "caregiver's burden" (cf. Degeneffe 2001; Gordon and Perrone 2004; Ingersoll-Dayton and Raschick 2004; Weitzenkamp, Gerhart, Charlifue, Whiteneck, and Savic 1997), there has been very little written about the experiences of the care recipient. The narratives of the men in this study illuminate the difficulties involved on behalf of the care recipient when trying to negotiate self-sufficiency, independence, and concern for another person.

When the "caring husband" identity was most salient for these men, they expressed concern for their wives' workload, time, and health. Gary offers an example of his awareness of the amount of assistance he requires in addition to his wife's work schedule:

> She works…10 to 12 hours every day, and twice a week, she has to go back [at night] after she comes home for dinner, takes care of me, then she has to go back…So, [it] is just a huge amount of work. Then add on the hour and a half in the morning, and half an hour in the evening. And another fifteen minutes for the middle of the day I see… so, she's looking at, over two hours every day, and sometimes more…

> taking care of me. So her days are very long, and I know it's a strain on her.

Anthony expresses his concern for his wife's needs in the following quote:

> It can be overwhelming. And I know it can. At times I wish I could just say, you know, go out of town. Go to your mom's or whatever, and stay a week or something. You know. And be to yourself. I know you probably want that time to yourself.

Awareness of their wives needs was one aspect of how these men saw themselves as caring and understanding of the demands they place on their wives' time and energy.

In an effort to alleviate some stress, these men try to be as independent as possible, which would fulfill their desire to be seen as independent men. As Gary says, he keeps trying to do more, so that she doesn't "go over the hump." The respondents report handling household tasks such as making appointments and dinner reservations; tasks that are typically handled by women in their identities as wives. For the men that could not drive, they try to use public transportation as often as possible to run errands or go to the gym. Like Anthony says:

> …that's why I try to be more independent as I can, to do different things more. And over the years, I started doing more and more, taking stuff away from her to have to do.

The scarce literature that exists regarding care recipients does examine the helping behaviors they exhibit. Ingersoll-Dayton and Raschick (2004) report that from the perspective of the caregiver, helping behaviors – those intended to reduce the stress on the caregiver – can often create higher levels of stress for the caregiver, especially when the caregiver is female. Respondents who reported more helping behaviors, such as trying

to make dinner or going grocery shopping, noted that sometimes helping was “not welcome” or “created more work” for their wives because they would “make a mess.”

Within the negotiation context, respondents found ways they could create a balance between the need for care, their desire for independence, and their identity as a caring husband. In order to accomplish this, the respondents had to lose independence in some areas of their life. The men who receive care from a spouse often gave up on wanting to do tasks in order to make things easier on their wives. Many of the things they report “passing” on would, in actuality, help them grow their social networks and relieve some caregiving burden. However, they know that initially it would cause more stress on their wives. Gary provides an example of how he had to cancel a weekend with friends because he knew it would be too much for his wife.

> I knew it was going to be too much of a strain on her. So I just cancelled the whole trip. Things I wanna do on vacation, I have to… I have to measure how much work it’s going to be for her to get me to where we’re going to go, and then I have to say, now do I really have to do that? No, I don’t *have to* do it, I’d love to do it. But a lot of the things I’d love to do I just can’t do anymore. Because I know it’s just more work for her.

By concentrating on his identity as a caring husband, he gives up on doing things he enjoys. In this situation, his caring-husband role is more salient because of the “commitment” he demonstrates.

Not sharing the fact that they are giving up things is also something that plays into the negotiation context. Sharing how they are giving up things might actually create more of a burden. For example, Anthony also does not share that he loses some of his

independence when he tries to be a caring husband and relieve the burden on his wife. Lifting her burden is more important to him than having control over his time; however, it creates a level of resentment on his part. He explains:

> I tell you one thing that bothers me, I don't really say it to my wife but like I said, that goes back to having to be compassionate on her part sometimes. Sometimes I may wind up going to bed when I [don't] want to go to bed. I still wanna be up doing stuff. But she gotta go to work the next morning so I gotta go down [to bed]. You know. It bothers me sometimes 'cause I feel like I'm a kid, you know. But I just didn't say, I never really did say that out to her, but it's like I say, I have to be respectful on her part.

Anthony is offering a presentation of self as a caring husband in this interaction when he wants to be independent and self-sufficient. He compares himself to a "kid," which is in contrast to his desired presentation as a man and husband. Anthony is also demonstrating the focus on role and commitment that is known to as part of symbolic interaction theory. Both respondents focus on having to "give up" something in order to maintain one identity (the caring husband) and to save time.

A second negotiation context within a caregiving marriage was combining caregiving and intimacy. Only one of the married respondents expressed the need to negotiate caregiving and intimacy, but I believe that is the result of differences in the level of impairment and sexual desire. One other respondent had a similar level of function; however, he was older than Gary and he expressed not missing sex. Allen was never told about Viagra during his rehab stay and he "just assumed it wasn't for" him. I

attempted to probe further about these topics and he did not offer much more understanding.

Gary, on the other hand, greatly misses sex and intimacy with his wife. Due to the salience of his identity as a caring husband, he is concerned about his wife's time and the amount of work she would have to do in order for them to be intimate. So he forgoes on pursuing sexual experiences with his wife. He must also negotiate with his identity as a care recipient and his wife as caregiver. This relationship is the largest barrier to their "love life". His wife assists him with all of his bowel and bladder care and bathing. He says that if they could move beyond this, then the level of intimacy would improve:

> Well, it's hard for her to think about us with the sex relationship when she's doing all my bodily functions. She doesn't really think of me much of any other way. So that's a stress. If I could get rid of the bowel program, I think that would really be a step in the right direction, as far as our love life.

Gary believes his wife's identity as caregiver is the most salient identity for her in their relationship because she cannot think about him as a lover. This negotiation is difficult for him, as he wants to fulfill his role as husband and sexual partner.

Summary

The men in this study experienced emasculation from various social contexts: space, employment, and marriage. They had to forgo social expectations of masculinity in order to negotiate each social context. Within all three areas of social life, men had to give up some level of independence and social interaction because of the constraints placed upon them. The social construction of space constrained their ability to enter, exit,

and move freely around buildings, and once inside, they were often isolated from conversations. Being denied employment had a direct impact on how these men viewed their masculinity. The black and white men constructed the context of race differently, but their experiences were more similar than they were different. Finally, the social context of marriage offers a unique experience for the respondents who were married and relied on their wives for some level of caregiving. These men had to negotiate identities as independent men and identities as caring husbands in order to receive the help they needed for daily living. These findings appear to be worthy of examining further to explore the identity and role of the care recipient.

CHAPTER VII: CONCLUSIONS

The goal of this study was to examine how men experience life with a physical disability. I was especially interested in how these experiences might be different or similar for black and white men. Overall, I found more similarities than differences among my sample of respondents, which surprised me given the literature detailing the extensive differences of black and white men, with and without SCI.

The theoretical frameworks of symbolic interactionism and the social construction perspective informed my findings. I explored the images and symbols that create meaning about disability, both for those who experience disability and for the people with whom they interact. The men in this study constructed three meanings related to disability: invisibility, hyper-visibility, and a ruined life. Most respondents had not consciously thought about disability or SCI before their injury. In more in-depth conversations, I found that they had preconceived notions about disability that influenced the early reactions to their injury. Through their own experiences and social interactions, they modified the meanings and found ways to form a new understanding of what living with a disability means to them.

For the respondents, the creation and modification of masculinity was an active process, which involved constant awareness that others were observing their presentation. Men created and performed normative masculinity by focusing on the extreme expectations of manhood: absolute independence, a normative body – especially an erect

penis – and extreme stoicism. One way to protect self-presentation in regard to body management and emotional strength was to maintain a boundary between the “knowing and unknowing.” Men modified their ideas of masculinity to include allowing help when necessary and communicating about sensation and pleasure during sex. In this study, men were very uncomfortable with emotional weakness, their own and other’s; therefore, they did not modify their meaning of “masculine as stoic” after their injury.

The men felt emasculated in three social contexts: space, employment, and marriage. They often had to forgo social expectations of masculinity in order to negotiate each social context. Within all three areas of social life, these men had to give up some level of independence and social interaction because of the constraints placed upon them. The social construction of space constrained their ability to enter, exit, and move freely around buildings, and once inside, they were often isolated from conversations. Being denied employment had a direct impact on how these men viewed their masculinity. Both the black and the white men constructed the context of race differently, but their experiences were more similar than they were different. Finally, the social context of marriage offers a unique experience for the respondents who were married and relied on their wives for some level of caregiving. These men had to negotiate identities as independent men and identities as caring husbands in order to receive the help they needed for daily living. These findings appear to be worthy of further examination to explore the identity and role of the care recipient.

This research was accomplished by examining the interpretive and symbolic meanings of disability and masculinity. Since much of the existing research available about experiences of disability is about women's experiences or men's sexuality, this research offers another layer to our understanding of how disability is experienced through the social constructions of masculinity. The individual narratives offered by these men allow for an examination of the shared meanings about disability and masculinity. These narratives also show how these meanings can create rigid categories that can be difficult to escape.

I expand the existing literature about experiences of masculinity by bringing in the voices of men who are visibly marginalized by society. Furthermore, I strengthen the literature relating to the study of disability by incorporating the experiences of men who receive care. This experience is valuable for understanding how men negotiate identities of a caring husband and an independent man within the context of marriage and the need for assistance. Additionally, this illuminates the ways that men actively construct masculinit(ies) in response to a sudden catastrophic injury, using Goffman's (1963) concept of drawing boundaries between the knowing and unknowing.

I complicate what little there has been written about the way blacks experience disability. Stuart's (1992) singular work on the subject states that disability and oppression work simultaneously and separate, not as a double oppression. The findings from this project are that the experiences of black and white men are more similar than different; however, in the context of employment, black men offer a different narrative

about why they are not getting jobs. They employ a color-blind narrative and assert that disability works as a way to alleviate differences between black and white men; however, the statistics do not mirror this assertion. A larger sample might yield more information about this process.

When examining this data, I found that masculinity was a more salient identity for these men than was race. There were many times in my analysis that I had to confirm the race of the respondent because the narratives were so similar to one another on discussions of sex, women, dating, access to space, and the desire to be independent; all aspects of identity that are typically assigned to masculinity.

This study presents a myriad of possibilities for future research. The ways that these men negotiate independence and receive care is one area that needs to be examined further. My findings suggest that normative ideas of masculinity encourage these men to assert their independence. Within the complex caregiver-partner relationship, it was often more important for these men to be simultaneously more and less independent in order to alleviate caregiver burden. This resulted in higher levels of resentment and lower levels of disclosure about dissatisfaction with the situation, as well as lower levels of social support, outside of the partner. This relationship should be explored in-depth by including more men who are in caregiver-partner relationships. Including women who are also care recipients in the analysis of this relationship could add further depth to the meaning of independence in this conceptual relationship.

Further theoretical sampling to include a better representation of social class, age, and level of function could add strength to this and future studies about the meanings of disability. My sample was similar in age to the average age of injury of the population as a whole. My findings related to psychological well-being varied with age at the time of interview and age at the time of injury. I think examining this relationship would be fruitful if viewed with a life-course perspective. Additionally, paying particular attention to social class might yield interesting results about how class affects notions of work and free time. Finally, I suggest that examining level of function will show how all three areas of experience I discuss are influenced by how much one requires assistance with Activities of Daily Living. Level of function differs from level of injury because each injury yields very different levels of function depending on the severity of the injury, time between injury and treatment, and other factors that are unknown about SCI and healing rates. These factors would address other areas of "marginalized masculinities" theorized by Connell (1995) aside from race.

As an exploratory project, there are some limitations to this study. First, the small sample size of each racial group makes it difficult to generalize beyond this sample. Few differences were found between black and white men in their experiences; however, a larger sample of both groups might have yielded more differences or further supported the similarities. My sampling technique of convenience sampling could also affect how much I can generalize these findings to the larger population of black and white men with disabilities. The men I spoke with had resources to access wheelchair sports, peer support

groups, and other social networks. Within the population with disabilities, just as in mainstream society, there are groups that are not connected to these resources. This limitation provides an opportunity for purposeful sampling of these men to examine their experiences. I am specifically thinking of the homeless and severely poor who are even more invisible than the men I interviewed.

This study also shows that our society is still a long way from accepting people with various levels of noticeable impairment. They are belittled and emasculated in public interactions and denied employment and access to public spaces in the built environment. Incorporating discussions of how discrimination against people with disabilities connects with other sociological discussions where race, class, and gender are often examined could further highlight the structural levels of oppression faced by people with disabilities. Undergraduate and graduate courses that examine inequality should also examine the inequalities experienced by people with disabilities. Without the discussions happening in the classroom, future scholars and educators will continue to allow people with disabilities to remain invisible in research and in society as a whole.

This study has implications and uses beyond the sociological and academic spheres. Primarily, this study could aid therapists and professionals in the rehabilitation setting that are responsible for patient and family education. As a person who has progressed through this program, the experiences of these men would have helped me understand some of the challenges my partner and I might face when we left the safe confines of the hospital hallways. Nurses, therapists, and professionals want to stay

positive for those they care for, but sharing information about the reality of having an SCI outside of the physical changes could help a person cope while facing such drastic life changes. During our interviews, these men continuously discussed ways that the rehabilitation process did not assist them in negotiating their new way of life. Offering more outlets for various expressions of masculinity through the rehabilitation process could fill this need. Additionally, educating partners about the challenges men will face in terms of sexuality and intimacy outside of physiological changes would allow for a more fulfilling sex life for both partners.

Overall, the study of disability and its intersections with other identities is full of possibilities for future research. This project has shown that it is worthwhile to examine the intersections of masculinity and disability because these concepts oppose each other in the ideological underpinnings of society. Furthermore, examining the opposing concepts through the experiences of men with different racial identities shows how masculinity is not a monolithic experience; rather it is continuously shaped by experiences of privilege and marginalization.

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APPENDIX A: FLYER

Research Study

As part of a master's thesis project in sociology at Georgia State University, I am conducting interviews with men about the personal meaning and experience of disability in their lives. The interview will last less than two hours and will be scheduled at a time convenient for you.

I would really enjoy talking with you if you:

- Were injured after the age of 18
- Are at least two years post-injury
- You have a noticeable physical disability

You can contact me at:
Alexis Bender
678-595-4080
socaab@hotmail.com

Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080	Study: Alexis Bender 678-595-4080

APPENDIX B: INFORMED CONSENT FORM

Consent Form

MA Thesis Project: Intersections of Race and Disability
Georgia State University
Department of Sociology

You are invited to participate in a project in which you will be asked questions about your personal experience of having a physical disability. Part of this project seeks to identify the different experiences of men who identify as white and men who identify as black. The interview is part of a research study to complete the requirements for a Masters thesis in Sociology at Georgia State University.

If you choose to participate, you will be interviewed for a time lasting between one and two hours.

There are no reasonably foreseeable physical discomforts or risks associated with your participation in this project, though answering questions about sensitive topics might make you feel a little uncomfortable. Still, the direction of the conversation is, to some degree, in your hands.

If, during the course of the interview, you feel the need to speak to a counselor regarding any discomforts that arise as a result of the interview, the interviewer will refer you to an appropriate counseling facility. In the event that you do not have a personal physician, the interviewer will refer you to the most appropriate public health facility. You will be responsible for any costs associated with this service.

Participating in the project is not likely to benefit you directly, but the knowledge that the interviewer gains about the personal experiences of people with disabilities of different racial backgrounds may contribute to a greater understanding of disability in society.

The interview will be taped and listened to by the interviewer. The tape will not be handed in to any person, nor will it be shared with anyone else, except for the purpose of transcription. The tape will be stored in a locked filing cabinet, in a locked room, without any identifying information for the duration of the study. After the study is complete, the tape will be destroyed. Also, you will not be identified by name in any paper or publication resulting from this interview.

You may ask questions about this project to the principal investigator (Alexis Bender, Sociology Department, Georgia State University, phone: 770-432-9338) or her advisor (Dr. Charles Gallagher, Sociology Department, Georgia State University, phone:

404-651-1853). The GSU Research Office of Research Compliance (phone: 404-651-4350) can provide you with general information about the rights of human subjects in research.

You may refuse to participate in this project, and if you do choose you participate you may stop at any time. You will not lose any benefits if you choose to withdraw from the project at any time.

You will be given one copy of this consent form to keep.

If you are willing to volunteer for this project, please sign below.

_____	_____	_____
Subject	Signature	Date
_____	_____	_____
Interviewer	Signature	Date

APPENDIX C: INTERVIEW GUIDE

Diagnosis & Rehab

I think a good place to start is if you would tell me everything you remember about injury.

If these don't come up:

Where were you?
Who told you?
How old were you?
What were your first thoughts?
How did you react?
How were you injured?

Did you know much about your disability before you were injured?

What did you know?
What do you know now that is different?
How have your feelings about your injury changed than when you first learned of your injury?

As you transitioned into the rehab side of things, what was that experience like?

What kept you going every day?
What was the hardest thing?
Who was there to help you?
What did you like most and least about it?
What are some stories from rehab you might want to share?

Meaning of Disability

Now that you have been living in the community and you are labeled as having a disability, what do you make of the word 'disabled'?

How would you describe someone with a disability?
How do you see yourself fitting in with these definitions?
How has this changed over time?

- Initial reactions
- Month
- Year
- Present

How does your disability affect your daily activities?

What types of things do you have to do now that you did not have to before your injury?
Do you think you have any advantages because of your disability? Has anything positive come about because of your disability? Do you have any good stories about positive things?
What disadvantages? Frustrations? Stories?

Work

Were you working when you were injured?
What did you do?
What did your work mean to you?

Are you working in the same field? What do you do now?
Is your work the same or different now? How? Examples.
- Duties
- Treatment
- Explain

How accessible is your workplace for you?
How accommodating is your company?

If not working, why not?
How do you spend most of your day now?
Do you wish you could work? Why?

How important is work to you?
What do you gain from working?

Health

Do you have any health concerns?
- Affect your life activities?
- Health before your injury?

What were some of your biggest emotional hurdles initially?
How did you cope with them?
How did your family and friends play a role in your coping and grief?
Now?

What do you think you face emotionally now? Examples.
What are the positive emotions?
What are the negative emotions?

Public Presentation

Do you think you present yourself to people differently now? How?
How do you present yourself when meeting people for the first time? (Details)
How do you think people see you?
After you get to know people, does this presentation change? How?
Are there places that you feel more comfortable going? Less comfortable?
What do you do in situations where you can no't access a building, restaurant etc.?
Do you feel more or less comfortable in public when you are with another person with a disability? An able-bodied person?

Private thoughts

What are the things you think about when you are by yourself?
Do you share these thoughts with others? Whom?
Why don't you share these thoughts?
Have you ever had suicidal thoughts? Are there times when these thoughts had more impact than others?

Have you hidden thoughts from people because you feared negative reactions?
What are some of them?
Have your private thoughts changed since your injury? How? Examples?

I have heard statements from men here talking about their body in a way that suggests dislike for their body or a feeling of disconnection – do you ever experience thoughts or feelings of being more or less connected to your body?

- When?
- Are there parts of your body that you feel more or less connected to? Examples?
- Do you feel differently about your body now than you did before your injury? How? Examples?

Masculinity

How would you define being masculine or being a man?
What makes someone a man? Examples?
Do you think that view or definition has changed for you over time?
How? What caused the change?
Did you see yourself as a man before your injury? During recovery? Now?
Did your ideas of 'being a man' affect the way you faced your recovery and rehab? How?

Do you ever try to do things to “prove” your masculinity? What? How?
If no, why not?

Were you involved in sports before your injury? How?
To what extent did sports play a role in shaping who you were?
After your injury, did you seek to find a way to fill that void? How?

Social Interaction

How has your peer group changed?
- Were your peers around after your injury?
- Do you rely on your friends to help you with daily activities?
- Is there a line you won’t cross when asking for help? What? Tell me more.
- Is the line different with different people? Examples?

What sort of relationship do you have with your family members?
How was your family there for you after your injury?
Have your views toward your family changed at all?
Do your family members help you with daily activities? Has this changed over time? How?
Have your relationships with any family members changed?

How do you interact with strangers in the community?
How do you think people see you?
Do people look at you any differently now than before?
Do you think people treat you any differently? How?
What are some of the positive things that occur in the community? Negative?
How do you respond to people (either positive or negative)?

Are you involved in a romantic or sexual relationship with anyone? Please describe this relationship.
Were you involved with this person before your injury?
How did you meet?
To what extent is your partner involved in caregiving and assisting you with daily activities? Tell me more about this. Do you think having your partner involved in caregiving is positive or negative? How? Examples?
What are the positive aspects of this relationship? Examples
What are the negative aspects of your relationship? Examples

If not involved (or if not with same partner from pre-injury), how do you meet potential partners?

Are there some potential problems when dating? Examples?

What are some things that go smoothly? Examples.

How do you go from meeting to dating? Are there any things you have to do that you didn't have to do before your injury? Examples?

Is sex something that has changed for you? How? Examples?

Do you think of sex differently? Intimacy? How?

Is (was) sex something that was hard for you to bring up with a partner?

What are some challenges you have when it comes to sex or intimacy? How do you deal with those challenges?

Are there things that you find more rewarding now than before? What? Examples?

How about children? Do you have children or want children?

How did your children react to your injury?

How did you explain it to them?

How do you think your injury affects your desire to have children?

Recovery

With the recent death of Christopher Reeve, it seems the talk of a "cure" has come back to the front-and-center – do you hope for a cure for yourself?

What do you think a cure would mean to you?

Are there things you do to anticipate a cure? What? Examples?

Do you think your idea of a cure has changed over time? How? What do you think brought about that change?

If we lived in a world where people with disabilities were treated the same as people without a disability, do you think a cure would be as important?

Where do you see the position of people with disabilities in the U.S. going?

Basic Demographics

- How old are you now?
- How do you define yourself racially?
- Where would you place yourself in terms of social class? Now? Growing up?
- What is the highest level of education achieved?

Other Topics

Is there anything I did not ask you about that you would like to share with me?