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PATIENTS, PARTNERS, AND PRACTITIONERS: INTERACTIONS AND MEANING-MAKING FOLLOWING SPINAL CORD INJURY

by

ALEXIS A. BENDER

Under the Direction of Elisabeth O. Burgess

ABSTRACT

Sustaining a Spinal Cord Injury at any point in time is life altering – physically, emotionally, and financially – for all persons affected by the injury, but it can place unique challenges on younger married couples. This study examines the transition to injury for 18 couples (ages 21-55). Data were collected using individual interviews with each partner at three time points following injury, as well as observation in the rehabilitation setting (Creekview). This resulted in 96 individual interviews and 300 hours of observation. Using a combination of the life course perspective and cognitive sociology as guiding theoretical frameworks and grounded theory analysis, I examined how the health care institution influenced the couples' relationships during their rehabilitation stay and the subsequent transition home. Overall, this study found that Creekview shaped a thought community that emphasizes a return to walking and high levels of physical recovery. Patients who achieved these goals constructed positive narratives about the future while those with lower levels of recovery constructed negative narratives over time. Additionally, because of the dominant medical narrative of *wait and see* regarding physical recovery, many respondents constructed fuzzy narratives about the future that reflect ambiguity about what life would look

like following injury. Additionally, Creekview staff and couples accepted and reinforced the dominant cultural narrative that women are natural caregivers, but larger social structures of class, gender, and the division of paid and unpaid labor work together to push some women into caregiving faster or prevent other women from engaging in caregiving. Expanding on Aneshensel et al.'s (1995) caregiving career, this study examines how younger couples move through the caregiving career when the expected outcome is not long-term care placement or death. This study identified three main types of caregivers, each with their own path of caregiving – Naturalized, Constrained, and Resistant caregivers. Overall, the transition to injury is complex for patients and partners and this study highlights some of the ways the marital relationship is affected by a non-normative, unexpected transition.

INDEX WORDS: Disability, Marital relationships, Family, Traumatic injury, Rehabilitation, Medical institutions

PATIENTS, PARTNERS, AND PRACTITIONERS: INTERACTIONS AND MEANING-MAKING FOLLOWING SPINAL CORD INJURY

by

ALEXIS A. BENDER

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

Doctor of Philosophy

in the College of Arts and Sciences

Georgia State University

2011

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Alexis A. Bender
2011

PATIENTS, PARTNERS, AND PRACTITIONERS: INTERACTIONS AND MEANING-MAKING FOLLOWING SPINAL CORD INJURY

by

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Georgia State University

August 2011

DEDICATION

This project is dedicated to my partner, Greg Brakel, who has provided me strength through our long journey together. I also dedicate this work to my mother, Helen Gallagher, who taught me to dream big and to never let anyone stop me from reaching my goals. I would not be where I am without these two wonderful people!

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First and foremost, this project could not have happened without the couples and practitioners who participated in this study. Their experiences provided meaning for me and the many couples who will follow after them and learn from their wise words. They opened their world to me at one of the most vulnerable points in their lives and for that I am so grateful. We met as strangers in a hospital, and I hope we left as friends. Their words helped me heal from my own journey into spinal cord injury. Thank you!

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I am not sure I have enough words to thank my amazing colleagues, friends, and family who have helped me through this whole process. There are far too many people to list individually, but in particular I am thankful for the support and encouragement of my mother, Helen Gallagher. She was always ready with food and words of encouragement, love, and pride. I am forever grateful for the support from the faculty, staff and fellow students in the Department of Sociology and the Gerontology Institute. I especially want to thank Christina Barmon, Saori Yasumoto, Beth Cavalier, Cindy Sinha, Elroi Windsor, and Molly Perkins for the never ending support and encouragement over the years. I am fortunate to have you all in my life. Kate Hannon, Melissa Zipfel Williams, Floren Ansley, and Stacey Pearce have all helped me survive

this process. They all kept me on task when necessary, listened to me vent, and understood when I needed to be left alone. Our BFast runs will not be the same without the constant need for me to discuss my dissertation. The support from Garry Schliefke and Maggie Cavalier made the massive amounts of data collected from this project a little more manageable. I am indebted to your ability and willingness to help with this project.

My partner, Greg, deserves the highest level of appreciation. He truly gives meaning to the word "partner." These past few years have been tough for us and his support and understanding have been priceless. He was always willing to read rough drafts (over and over and over again) and to do what needed to be done to keep our house from falling apart. He knew when I needed a night out, when I needed to sleep in, and when I needed to stay up all night to get something done. I think we can check this off the to-do list!

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CHAPTER 1

INTRODUCTION

Over the past decade, advocacy groups have increased public awareness about Spinal Cord Injury (SCI). Specifically, the high profile Christopher and Dana Reeve Foundation[1] has facilitated greater awareness of SCI and advocated for more innovative medical and rehabilitation research. Furthermore, advances in technology and pharmaceutical interventions have resulted in new approaches to the treatment, rehabilitation, and quality of life for persons with SCI (American Academy of Physical Medicine and Rehabilitation 2008). As a result of both scientific research and public advocacy, the experience of living with SCI is changing for individuals and their families.

Approximately 11,000 people of all ages will sustain a Spinal Cord Injury (SCI) each year and almost 300,000 people are currently living with SCI in the US (National Spinal Cord Injury Statistical Center 2009).[2] There are many causes of SCI with nearly half (47 percent) occurring because of automobile accidents, followed by falls (23 percent), violence (14 percent), sports (9 percent) and other unknown causes (6 percent). SCI disproportionately affects men (78 percent), primarily because of risk taking behaviors; however, there has been a slight downward trend in the number of males injured over the past 35 years (82 percent prior to 1980).

Significant changes in racial distribution of SCI have been noted over time as well. Currently, injury rates by race show that 63 percent of injuries occur among whites with blacks at 23 percent and Hispanics at 12 percent. According to the 2000 U.S. Census, whites account for

---

[1] Although the Christopher and Dana Reeve Foundation was founded in 1999, it is the continuation of 17 years of advocacy work for SCI. After his highly-publicized 1995 accident that resulted in a SCI, Christopher Reeve became involved in the American Paralysis Association, founded in 1982. The two groups merged in 1999 to form the present day foundation with the Reeves lending their celebrity status and their passion for changing the future for people living with SCI (www.christopherreeve.org).

[2] Unless otherwise stated, all statistics come from the National Spinal Cord Injury Statistical Center.

75 percent of the population, blacks account for 12 percent, and Hispanics of any race make up 15 percent of the population (2000). Clearly, there are a disproportionate number of blacks who sustain SCI compared to whites and Hispanics. Prior to 1980, 77 percent of new SCI cases were among whites, 14 percent were black, and 6 percent were Hispanic. The 1980 census figures show 86 percent of the population as white, 10 percent black and just over five percent of the population was Hispanic (Gibson and Jung 2002). While it appears that a general population shift has occurred over time, minority groups, especially blacks, are disproportionately affected by SCI.

SCI primarily affects people during their early adult years with the most frequent age of injury at 19 and an average age at the time of injury of 38 (National Spinal Cord Injury Statistical Center 2006). This age is when many people are in the first decade of marriage, engaged in a career track, full-time employment, and also might have young children. There are not as many details about relationship status as there are about other demographic characteristics. Among the cases in the NSCISC database (collected annually from 1973 to present), most people who experience SCI are single at the time of injury (52 percent), which makes sense given the young age of many people who experience SCI. For those who are married (32 percent) or who eventually marry, the likelihood of their marriage remaining intact is slightly lower than the general population. There is an increase in the percentage of divorced people in the database at five years post-injury with a continued increase through year 25.

Sustaining a SCI at any point in time is life altering – physically, emotionally, and financially – for all persons affected by SCI, but it can place unique challenges on younger married or cohabitating couples for a number of reasons such as shorter length of marriage or having less financial and career security. Both partners involved in the injury face uncertainty

about the future and the concern about whether their relationship will "survive" might be equally strong for the non-injured spouse as it is for the injured spouse (Kreuter 2000). The presence of SCI might magnify or modify existing problems in a relationship, create a burden for one partner, or impede life satisfaction for both partners (Chan 2000). Sociologists are just starting to examine relationship dynamics in light of illness and trauma, especially in relation to younger couples. Additionally, not many researchers have paid attention to how social, institutional, and familial support can affect couple adjustment to SCI.

PERSONAL EXPERIENCES AS A PARTNER

This project is a true extension of C. Wright Mills' "Sociological Imagination." Mills suggested that people should examine their personal experiences in relation to the social factors that shape these experiences (Mills 1959). At the end of my first year of graduate school, my boyfriend at the time was in a skydiving accident that changed every aspect of our lives in less than a second. I remember it was a sunny spring day and I was enjoying my last afternoon of fun before I had to go home and finish all my final papers. When I got to the car, I listened to a voice mail on my phone and I went from a light-hearted conversation with a friend to a stunned, shocked, panicked scream. Greg had been taken by helicopter to a trauma center in Alabama. His heart was beating after four minutes of CPR, but he was not breathing without assistance.

I arrived in Alabama three hours later and the days following that are still foggy in my memories. Our families and friends came from everywhere and we moved between shock, horror, disbelief, and sadness as the doctors told us that Greg might never breathe without a ventilator or even live through the night. Day after day, we experienced the emotional roller coaster of trauma. That slowly subsided. He became more alert every day. The trauma gave way to routine. I wondered what this life would bring. I selfishly wondered about dating and sex and nights on the

town after too many bottles of wine. Three weeks after the injury, Greg was transferred to a spinal center in Atlanta and the focus was recovery and independence, whatever that meant! We settled into our routine. He regained movement and the ability to breathe without assistance. Things were positive for him, physically. He seemed optimistic with friends and family, but when we were alone there was a dark side. He was horribly depressed and suicidal. He asked me on numerous occasions to help him die. I couldn't do that! I thought things would be fine. We could get through this mess, maybe.

I think I was in a state of denial. I had no one to tell me otherwise. My friends were there, but distant. I forgot how to interact socially as a 28 year old. My friends wanted to go out, I had to learn about bowel and bladder management. People stopped calling. I stopped asking for help. I went through classes at the rehabilitation center to learn about SCI in two days. Greg's mother and I were assigned to the same class. Perhaps one can imagine my discomfort learning about sexual function while sitting next to my boyfriend's mom. I did not ask any questions that day. I walked away from that experience thinking that the people who were supposed to teach us about everyday life with SCI had no clue about human interaction.

After we had all completed our training, about three months after the injury, Greg was sent home. His mother and I took over every aspect of his care, which was a 24 hour operation. We helped him eat, wash, use the toilet, dress, and rolled him over in bed four times at night. We traded night and day shifts. She worked the "day shift" so I could go to school and do my work, and I worked the "night shift" so she could sleep. We lived by this schedule for four months. All of the sudden, the swelling started subsiding in his spine and he made drastic strides toward recovery. It was like a switch turned on and he gained so much back. Seven years later, he still makes progress. He can walk nearly a half mile when he wants to, he works full-time, and he

sometimes even helps with the housecleaning. His depression goes into hiding for long periods of time, but it is never gone. It has been a long, hard road! But we have made it thus far.

Life with SCI is not only my partner's, but mine as well. I live the daily struggles that he lives, not physically but emotionally. We have lost friends and we have gained friends. We do different things for enjoyment. We have to sit home when people have events that we can't access because of stairs or small bathrooms. We have to leave events early because of bladder management. I have to do things alone when other people can include their partners because of accessibility. But we have also grown as people. We offer support to other couples with SCI and try to find ways to be more positive about change. Mostly we have grown as a couple because this injury ripped our façades off. It is hard to maintain privacy, modesty, and mystique when something like this happens. We have revealed parts of ourselves to each other in ways that we could not have imagined. And many things have stayed the same. After it all, we do still enjoy our sushi date nights and good wine.

At the time of his injury, I was working toward a Master's degree by studying housing displacement in Atlanta. Although his mother gave me time to do my school work, I found that no matter how hard I tried, I could not force myself to read one more article about housing. Rather, I spent all my time looking for information about SCI and how it alters a person's life, which I found little in the way of sociological research. I never imagined how much this would change *MY* life. I never knew anyone who had a SCI or used a wheelchair and I had never been exposed to any disability research in my education, including an inequality class. I abandoned my original thesis topic in hopes of offering something to the sociological discussions of inequality and marginalization by researching disability. In my thesis (Bender 2006) I looked at the intersections of race, masculinity, and SCI. This project is in part an extension of the last and

an extension of my own life. This dissertation is an examination of how SCI affects marital relationships and how the rehabilitation institution shapes couples' experiences as they move through this transition

SIGNIFICANCE OF THE STUDY

The primary goals of this study were to investigate how relationships change, positively and negatively, or remain the same following SCI in younger married heterosexual couples and what role the rehabilitation setting played in adjustment for both sides of the couple. In particular, I explored the couples' experience of the rehabilitation setting, adjustment to the caregiving role, changes in informal social networks and shared activities, and changes in gender roles in the relationship.

It has been argued that the marital dyad and other intimate relationships are perhaps the most important "social context within which the psychological aspects of chronic illness are managed" (Rodgers and Calder 1990:25). I assert that the sociological aspects of chronic illness and injury are also negotiated within the context of rehabilitation setting. The contributions of this study are numerous. First, many studies surrounding relationship change after injury and illness are grounded in the clinical fields. This study removed SCI from the clinical world, which represents a medical model of disability, by applying key sociological theories to the understanding of its effects on relationships. Second, this study used qualitative methods that have not been sufficiently employed in the previous literature. Qualitative methods are appropriate for examining the intricacies of how couples negotiate SCI. Third, using a life course perspective, this study focused on younger couples (under the age of 55) as a way to examine the

transition to injury as an off-time event for both the patient and the partner.[3] Since a large number of studies about relationships and illness focus on older couples, this study will contribute to the life course perspective by examining how one's location in the life course and the timing of events influences how couples negotiate SCI. Fourth, combining the life course perspective and cognitive sociology is a valuable example of how sociologists can synthesize two complimentary theories to explain one phenomenon. And finally, we know little about the broader levels of social support that couples receive during their transition through the rehabilitation setting. While previous research indicates that partners feel left out of the process, it is unknown if rehabilitation professionals view their role as needing to be inclusive of partners. This project includes interviews[4] with and observations of rehabilitation practitioners who provide support to couples as a way of examining the cognitive boundaries practitioners draw with regards to their role as a giver of support.

RESEARCH GOALS

The goals of this exploratory qualitative study were to examine how younger marital and cohabiting couples negotiate their relationship following SCI and to examine how their interactions with practitioners influence their experiences in the first months following injury. I hope this study will increase our understanding of how couples negotiate non-normative transitions during their mid-adult years. Additionally, this study will increase our understanding of how interactions with practitioners shape the meanings associated with such transitions. The

---

[3] I use the terms "patient" and "partner" throughout the dissertation to denote who has the physical injury and who does not. This language is problematic because it is not person centered, but after much deliberation I decided to keep this language for a two reasons. First, because of the gender mix of my participants it would be difficult to clearly discuss which partner I was referring to. For example, the use of the term "wife" would signify the partner in most cases, but not all. Second, I refrained from using the language of injured or non-injured partner, because it is my belief that both partners experience the injury, albeit with different emotions and reactions.

[4] I formally interviewed three counseling professionals and conducted a number of informal interviews with physical therapists, peer counselors, and family support staff as a part of this project.

results of this study will hopefully inform future efforts to create training programs for staff working with couples and will contribute to materials for couples to use during support groups and training sessions. Furthermore, it will make theoretical contributions to family and disability studies.

The specific goals of this study were:

Goal 1: To examine how couples construct their relationship before and following injury.

- How do non-injured partners view their injured partner (physically and psychologically) now and before?
- What do they think they have lost/gained as a result of the injury?
- What does this injury mean to their future?
- What narratives do they construct about their past, present, and future?
- What strategies do they use to negotiate their own sexual and intimate needs?

Goal 2: To examine how practitioners shape the experiences of couples following injury.

- How do practitioners *construct boundaries* between patients and partners?
- How do they *communicate* about future outcomes and expectations?
- What do they say/do not they say about *future expectations* to patients and partners?
- How do couples *make sense* of information received from practitioners?

Goal 3: To examine what it means to experience SCI as a non-normative event.

- How are their social networks changing because of the injury?
- How do/did they negotiate the household division of labor?

- How do they think their daily life is different than it should be?

Goal 4: To examine how individual, family, social, community, and rehabilitation centers influence patient and partner experiences of SCI.

- What is the influence of individual factors (e.g., level of injury, gender, age, race, personality, economic status, religious beliefs, etc) on the experience of SCI?
- What is the influence of family factors (e.g., extended family resources, family cooperation, interaction, geographic proximity) on the experience of SCI?
- What is the influence of social networks (e.g., number of close friends, friend involvement) on the experience of SCI?
- What is the influence of rehabilitation centers (e.g., education of staff, interaction of staff with both partners, education of partners and families) on the experience of SCI?

In this chapter, I provided an overview of the goals of this research. In the next chapter, I summarize the literature regarding relationships following traumatic injury including social support, caregiving, and the role of professionals in the rehabilitation process. In Chapter 3, I discuss my theoretical frameworks for the study, the life course perspective and cognitive sociology. In chapter 4, I cover my methodological design and processes, which includes access to participants, sampling, data collection, and data analysis. In chapter 5, I provide an overview of the rehabilitation center, which will provide a context for the remaining chapters. In chapter 6, I examine how couples construct trajectory narratives following injury. Chapter 7 explores how couples negotiate the care contract. Finally, chapter 8 provides conclusions, theoretical implications, and future directions for this research.

CHAPTER 2

LITERATURE REVIEW

SOCIAL SUPPORT

Marital Couples

Social support is important in all aspects of life, especially when facing something as life altering as SCI. Social support comes from many sources including family, friends, medical professionals, and rehabilitation professionals. Thoits (1995) argued that social support serves two important functions in our lives. First, the amount of social support has a positive effect on our general well-being and second having social support serves as a buffer to stressful situations. One troubling finding in SCI research is that many people with SCI have less social support when compared to the general population (Holicky and Charlifue 1999). One study that examined young couples (before retirement age), Parker (1993) found that couples where one partner experienced an injury were virtually without practical and emotional support at a time when they needed it most.

Among those with disabilities extended social support may be lost over time and the primary source of support is often an intimate partner, leaving them vulnerable as they age. Additionally, this singular source of support places an added burden on the supporting partner knowing that they are the only person their disabled partner relies on for care and support (McColl et al. 1999). McColl et al. (1999) gave two reasons for this reliance on the spouse. First, marital relationships are robust on the face of stressors and have less rigid rules for reciprocity than other relationships. Second, spouses viewed the relationship from a long-term vantage point and were perceived as knowing the “essential” person. In a study of caregiving wives, Gosling and Oddy (1999) found that many of the caregiving wives were without social support, including

paid social support. Many felt that they needed counseling, but did not have access to such resources.

Having a partner as a support person can be very beneficial to a person with SCI. Being married helps many people make the transition to disability or living with chronic illness. In a study comparing single and married people with disabilities, Putzke, Elliot, and Richards (2001) found that single individuals report lower levels of life satisfaction and higher levels of handicap than married individuals. And married individuals showed a better adjustment to SCI than single people, perhaps because marriage offered a buffer against the changes and challenges faced by people with SCI in the first year following injury. Harrison et al. (2004) also reported positive benefits of marriage, that marital status was positively related to acceptance levels of disability. They found that people who remained married had a higher acceptance of disability as compared to those who were not consistently married. They also found that regardless of marital status, women had higher rates of acceptance of disability over time than did men (Harrison et al. 2004).

While marriage serves as a buffer to some of the effects of disability, spouses can be a source of criticism or may reinforce disability by helping too much (Holicky and Charlifue 1999; Putzke et al. 2001; Mills and Turnbull 2004). Mills and Turnbull (2004) found that partners can increase psychological intimacy by boosting the self-esteem of the traumatized partner with compliments or may in fact lower their self-esteem and self-confidence with critical comments. Additionally, married people with SCI have noticeably lower levels of independence when compared to single individuals with disability. Perhaps it is the result of shared activities of the couple or that the spouse might perform activities out of convenience, consideration, or role fulfillment rather than the actual need of personal assistance (Holicky and Charlifue 1999).

In a widely cited study comparing preinjury marriages (marriage before injury) to postinjury marriages (marriage following injury), Crewe, Athelstan, and Krumberger (1979) found that those in preinjury marriages had lower levels of motivation for independence and those in postinjury marriages had higher levels of employment and less physical assistance from their spouse. However, Kreuter, Sullivan, and Siosteen (1994a) found no differences among lasting preinjury and postinjury couples in terms of emotional attachment and relationship satisfaction as a whole. In my own study of 20 men with SCI, I found that men in preinjury marriages felt the need to put their needs and motivations aside to care for their wives emotional and time needs (Bender 2006). This could be one explanation to the lower levels of motivation reported by those in the study conducted by Crewe et al. (1979).

Role of Professionals and Practitioners

Many of the available studies about SCI and traumatic injury are from the rehabilitation and clinical fields and, as such, they offer various clinical implications for rehabilitation facilities. As one who has gone through the rehabilitation process as a partner, I can say that many of these findings would have helped my own transition into life with a partner with SCI. However, there are not many studies that focus on the couple as a dyad within the rehabilitation setting. Gosling and Oddy (1999) reported that several women in their study stated that, as partners, they felt left out of the rehabilitation process and the resources available to them were scarce.

A positive rehabilitation setting that is supportive of couples as a whole as opposed to two different entities could mitigate the negative effects of SCI and other injuries (Chan 2000). Additionally, some researchers suggested that the rehabilitation institution should pay attention to marital stability and that it is important to have well designed marital interventions to decrease marital distress resulting from SCI (Kreuter 2000). Positive rehabilitation outcomes are related to

the strength and quality of marital relationships and that marital status is a predictor of level of independent living (Kester et al. 1987). Second, counseling both patients and partners may result in long-term benefits by reducing burdens in the couple relationship (Kreuter 2000). And finally, by including the partner in the rehabilitation process, the couple can focus on activities that they both feel are important therefore reducing strain on the couple (Eriksson, Tham, and Fugl-Meyer 2005).

IMPACT OF INJURY ON RELATIONSHIPS

Kreuter (2000) asserted that it is possible that the greatest test of a marriage or relationship is one presented by a traumatic SCI. Many studies have found that patients and their partners experience various negative psychological reactions to the onset of disability and chronic illness (Kowal, Johnson, and Lee 2003) Additionally, injury can cause economic and emotional strain on a couple (Chan 2000). Yet, there are mixed findings as to whether physical illness causes an increase, decrease, or no effect on marital satisfaction (Schmaling and Sher 2000).

Spouses of men with Traumatic Brain Injury (TBI) reported changes in roles and altered expectations of their life with their partner. Some women felt that their role was no longer as a spouse but more of a mother or parent to their husband (Gosling and Oddy 1999) and others had a difficult time living with a spouse who is substantially different following an injury (Degeneffe 2001). As a whole, these women reported that the relationship changed and they felt the marriage was not equal, their spouse did not share in household tasks, nor did the injured spouse provide much companionship. These findings were echoed in a recent that found that caregiving spouses experience loss and a lasting change in relationship dynamics following SCI (Dickson et al. 2010). In a clinical nursing study, Eriksson and Svedlund (2006) interviewed four female

spouses whose partner has a chronic illness. They found that in these women's lives they felt detached from their partner's lives and they experienced loneliness because of their partner's disability. In a joint survey of 55 couples with a mean age of 51 for the brain-injured person, Eriksson et al. (2005) found that only one third of the couples were satisfied with their life.

In studies comparing people with and without disabilities, Urey and Henggler (1987) found that SCI couples who reported having problems expressed dissatisfaction with sexual relations and low levels of communication in comparison to couples who did not report pre-injury dissatisfaction and to all persons without SCI. Taleporos and McCabe (2003) examined different patterns of marriage and satisfaction for people with and without a physical disability. They found that among those with physical disabilities, men were more likely than women to be single. Their findings also showed that people who were single reported higher levels of depression than those with a partner. Relationship status was also related to sexual well-being with singles reporting lower levels of sexual satisfaction and sexual esteem. However, married respondents reported lower levels of sexual well being than those with partners they do not live with.

Mills and Turnbull (2004) also examined the effects of injury on intimacy and sexual well-being. In a study of men with Post Traumatic Stress Disorder they found that traumatic injuries can cause changes at the partner level and also has "ripple effects" to relationships with friends, family, and co-workers. Those with Post Traumatic Stress Disorder had an especially difficult time developing and maintaining intimacy with their spouse or partner. The ripple effects described by Mills and Turnbull (2004) could also affect the level of social support one would have access to following injury.

Not all changes and challenges faced by couples with injury or trauma are negative. Some couples might experience positive changes following a traumatic event. Kester et al. (1987) found that couples do experience some positive changes following SCI including feelings of closeness, increased communication, and spending more time with spouse and children. Communication and problem solving are crucial to the success of able bodied couples and might be even more important among SCI couples (Kreuter 2000) and those couples that show positive communication and problem solving also have positive outcomes following injury (Beauregard and Noreau 2009). Chan's (2000) study of couples in Hong Kong had similar findings for some couples. Other studies have found little difference in communication and problem solving between couples with and without SCI (Kreuter, Sullivan, and Siosteen 1996; Young 1998). Other positive changes present in the literature are a feeling of greater commitment, continuing friendship, and uninjured women feeling as if they had more control in their own lives (Gosling and Oddy 1999).

A few studies have explored reasons for staying in marriages following SCI or TBI. Chan (2000) found that spouses reported staying out of traditional Chinese expectations of obligation to care for their spouse and to not regard caring as a burden. Some couples remain together because of a lack of alternatives (Parker 1993). And others report staying in the relationship out of concern for the injured spouse's future (Degeneffe 2001). Another reason for staying in caregiving relationships was hope for the future. In a study on caregivers to people with mental illness, many caregivers stayed in the relationship because they were able to hold on to some form of hope, even when the situation was rather grim. Also, caregivers frequently revised their expectations for the relationship as time passed and illness became a part of personal identity (Karp and Watts-Roy 1999).

SPOUSAL OR PARTNER CAREGIVING

Perhaps the most researched area in the area of marriage and illness is caregiving. Spousal caregiving has received a lot of attention in sociology, nursing, rehabilitation, psychology, and gerontology. Spousal caregiving is unique from other kinds of caregiving because spouses provide care for longer periods of time and tolerate higher levels of disability than other types of caregivers (Biegel, Sales, and Schulz 1991). Additionally, spouses provide 25 percent of care to older adults (Calasanti and Slevin 2006) and a married person will turn to their spouse first for care, regardless of gender (Kaye and Applegate 1990). While much has been written about this dynamic, little has been written about younger couples who are in caregiving relationships (Habermann 2000; Gordon and Perrone 2004).

Additionally, few studies focus on the care recipient or on both sides of the caregiving relationship regardless of the connection (spouse or not). Lyons et al.'s (2002) study focused on elderly caregiver-receiver dyads. This study was one of a few that included the perspective of both sides of the caregiving relationship; however, their focus was not on marital partners. Another article from the counseling and therapy fields consisted of 45 dyads with interviews and surveys taken at two time points. The author examined the ways that patients and caregivers experienced stress and how they coped with Multiple Sclerosis. Again, this study included all unpaid caregivers, including friends and family (Pakenham 1998).

Regardless of the lack of existing literature examining both care giver and care recipient, it is known that caregiving relationships can be very difficult for both partners in the relationship. One area of concern in couples with SCI is that the partner must often play the roles of lover and caregiver, which can have a serious impact on the relationship (Kreuter 2000). Caregiving spouses expressed wanting to be loved as a spouse and not as a care provider (Eriksson and

Svedlund 2006). Caregiving can change the balance of power in a relationship, possibly placing the relationship at risk. Couples who have difficulty maintaining equity following SCI, as is often seen in caregiving couples, might have a more difficult time maintaining the marriage (Kreuter 2000).

In their study of partners of SCI patients, Kreuter, Sullivan, and Siosteen (1994b) found that caregiving has a negative influence on a couple's relationship. These findings were supported by Weitzenkamp et al. (1997) in a longitudinal study of 124 spouses. They found that spouses who are also in a caregiving role experienced more stress, fatigue, and depression than their own partners and other spouses who are not caregivers. In fact, in one study researchers found people providing care to a spouse with a disability were six times more likely to experience anxiety or depression than non-caregiver spouses (Cannuscio et al. 2002). This finding was elaborated on in one of the few studies that I found using a life course perspective. Choi and Marks (2006) examined whether marital disagreement before entering a caregiving relationship predicted differences in changes in happiness and depressive symptoms because of the transition to caregiving. They found that compared to non-caregiving couples, new caregivers to a spouse had higher rates of depression and decreased marital satisfaction when reporting marital disagreement before becoming a caregiver.

Not surprisingly, research has shown gender inequalities in the caregiving relationship. Using data from the National Long Term Care Survey, Ingersoll-Dayton and Raschick (2004) found a gendered relationship between caregiver stress and problem behaviors of care recipient. They found a moderating effect on the relationship between problem behaviors and caregiver stress when care receiving wives engaged in helping behaviors. However, they did not find a similar effect when husbands were the recipients of care. According to Shackelford, Farley, and

Vines (1998) married women with SCI were more likely to have a paid caregiver while married men with SCI were more likely to receive their care from their spouse. Additionally, within the context of marriage and caregiving, Noël-Miller (2010) found that although married people with disabilities receive more hours of care than non-married people, women with disabling conditions receive fewer hours of care than husbands. These findings are in line with previous research by Spitze and Ward (2000) who found that wives benefit less from spousal caregiving than do husbands.

SUMMARY

The impact of SCI and other traumatic injuries on the couple relationship has been examined within the disciplines of nursing, psychology, and healthcare. Over the past 15 years, sociologists have begun examine how the personal trauma of injury has overarching implications for relationship and family dynamics (Chan 2000). The existing research highlights the importance of social support at various levels for both the individual and the couple. Furthermore, research shows that some aspects of the couple relationship change following injury while many features do not change. One of the largest gaps in the literature is the lack of research that includes both sides of the couple. Many of the findings about social support and caregiving focus only on the caregiver, which leaves the person who receives care without a voice and very little research exists about social support from rehabilitation practitioners. Furthermore, much of the research examines older couples and few include SCI.

CHAPTER 3

THEORETICAL FRAMEWORKS

In the previous chapter, I outlined the previous research related to injury and marital relationships. In this chapter, I describe the two theoretical frameworks that I used to examine how people make sense of the transition to life with injury. Sociological theory offers insights into the interactions of individuals and society. While there are a number of studies that examine the importance of social support and the impact of caregiving, not many take the perspective of the injured spouse or the couple as a dyad. Furthermore, researchers have not examined how couples and health care practitioners construct meaning surrounding the experience of SCI. In this study, I intend to explicitly draw on two theoretical perspectives, *Life Course* and *Cognitive Sociology*. The life course perspective is a useful tool for examining how the interactions between structure and agency shape the ways individuals experience life events over time while cognitive sociology is valuable for understanding how individuals "think" about their lives.

PERSPECTIVES ON THE LIFE COURSE

Over the past few decades, the life course perspective has emerged as a valuable tool for examining life events and life change. The life course perspective has theoretical roots in the study of social history and theories of individual and family development (Bengtson and Allen 1993). Much of the life course scholarship has conceived of the life course as a natural, systematic progression of individual's experiences as they move through time (Clausen 1986). This tradition of scholarship is guided by how the events in an individual's life, in the form of event histories or trajectories, compare to other persons or groups in terms of timing, duration, and rates of change (Giele and Elder 1998). For the couples in this study, the event of SCI might vary depending on multiple aspects of their lives. The life course perspective, like developmental

psychology, says that what an individual experiences before injury will affect how they experience life after injury. The life course examines all the experiences in one's life, which allows for various roles and events that might or might not proceed in any particular sequence. While we anticipate events will occur in a structured order (i.e., aging then disability), we know that events frequently do not follow our anticipated sequence (i.e., disability at 30). Additionally, the life course perspective allows us to examine the impact of change at different points in a person's life and there are many benefits of using this perspective, all of which stem from the guiding principles of the framework.

The life course perspective in its original conceptualization relies on four basic principles: location in time and place, timing in lives, linked lives, and human agency (Giele and Elder 1998).The first three are most applicable to this study. First, *location in time and place* refers to the cultural background that individuals experience both in terms of social and physical context. Time and place shape the trajectories of family, education, work, and they in turn influence behavior (Giele and Elder 1998). For example, a person who experiences SCI in 2008 will have a very different experience than a person who experienced one in 1985 before the passage of the Americans with Disabilities Act that shaped the cultural context of disability in America. Because of the importance of time and place in life course scholarship, this project aims to capture how these couples transition through time by using three interview points. The three interviews will use a combination of retrospective and prospective questions to examine how these couples experience this transition over time. The second principle, *timing in lives* refers to when events occur and it is most crucial to understanding events in the life course (Giele and Elder 1998). The way individuals measure their successes in life is frequently through the element of timing, thus the ways people view their life events as being "off-time" can have social

ramifications and result in different trajectories in their life course. Within the scope of this project, I am focusing on younger couples (before the age of 50) as a way to examine the transition to injury as an off-time event for both the patient and the partner. This event, because of its timing, could have ripple effects in terms of social interaction with friends and family as well as feelings of isolation within the couple. The third aspect of life course perspective is the concept of *linked lives* (Giele and Elder 1998). All aspects of an individual's life are interdependent, rather than separated from one another. People who experience SCI might find that it will affect other aspects of their life such as social relationships and workforce transitions, not just physical changes. Additionally, lives are linked when people share the same social worlds. This concept is especially true in families and dyadic relationships. These couples' lives are also linked to the rehabilitation professionals they interact with following injury. The patient and their partner's understanding of injury will be shaped by the information they do, or do not, receive from counselors, physicians, and family educators.

More recently, sociologists have developed alternative perspectives for studying the life course and the inherent aspects of age-related experiences. For example, researchers are examining how meaning is assigned to these life experiences using a *constructionist perspective* (Holstein and Gubrium 2007). The constructionist perspective does not take set life transitions or stages for granted; rather it examines how people construct meaning in regards to the life course (Holstein and Gubrium 2007). As with most scholarship, there are various ways that this perspective is applied. "Meaning-making," however, is central to all applications of the constructionist perspective. Holstein and Gubrium (2007) identify two main approaches to the constructionist perspective. The first examines how meanings are constructed "*through or across the life course,*" while the other focuses on how the life course is constructed and "*used*" to

understand how meanings are shaped in relation to time (Holstein and Gubrium 2007:337). Scholars that follow the first line of scholarship assume that life follows a continual path from birth through adulthood through old age with various discrete stages along the way. This approach focuses on how meaning is created as one moves through these stages and to the changes and transitions between stages. The second approach identified by Holstein and Gubrium (2007) is grounded in the ethnomethodological tradition. This approach also pays attention to how we construct meaning, but examines how the stages of the life course are constructed rather than viewing them as natural. Those who use this framework are interested in how individuals actively "interpretively construct" and use the life course to understand experiences. This perspective is helpful for examining how people use narratives to construct meaning about life transitions.

The *constructionist perspective of the life course* flows from the social constructionist perspective which 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 what they see as reality (see also Thomas and Thomas 1928; Blumer 1969). Berger and Luckmann (1966) viewed the reality of everyday life as an ordered reality. They argued that individuals assign meaning to the world through social interaction and language. Social interaction in everyday life has an impact on how people experience a catastrophic injury. For example, I sought to understand what it means to become a caregiver. In this study, partners did not just turn into a caregiver. Rather, "being" a caregiver involved a construction of identity that was shaped through interactions with others.

COGNITIVE SOCIOLOGY

Cognitive sociology complements the constructionist perspective of the life course. Cognitive sociology offers an additional explanatory framework for understanding how individuals make sense of the world around them. A key aspect of cognitive sociology is the way that it attempts to determine why people think in ways that are similar to or different from others' ways of thinking (Zerubavel 1997). One way we recognize similarities or differences in thinking is by examining the different "thought communities" (Zerubavel 1997:9) to which we belong. Thought communities develop in relation to other people and are the product of shared social experiences. Ultimately they shape the way we think as individuals (Zerubavel 1997). Thought communities can include nations, professions, cohorts, collectors, or patients. For example, people who experience SCI in the United States would already be members of the thought community of Americans, which might be different than people who are injured in Sweden. Americans value strength and independence and devalue people who need assistance, especially men (Kimmel 2006). This cultural value influences how participants think about disability and injury when it occurs. Additionally, they would join the thought community of rehabilitation because of the shared experiences of going through the rehabilitation process, using a wheelchair and having physical paralysis. People belong to multiple thought communities at any point in time; however, some thought communities can have greater influence on how we perceive things than other thought communities (Zerubavel 1997).

One possible way to determine the effect of being a member of a thought community is through the analysis of the narratives of its members. This project includes narratives of people in the American thought community in general and specifically from couples who have entered the thought community of rehabilitation involuntarily as well as the practitioners who have

entered voluntarily. This analysis is guided by six cognitive acts Zerubavel (1997) identified as central to cognitive sociology: *perceiving, attending, classifying, signifying, remembering,* and *timing.* Although these six cognitive acts are in fact conducted by individuals with their own "cognitive idiosyncrasies" (Zerubavel and Smith 2010:321), these acts are affected and constrained by the various thought communities we belong to. Within the context of disability and the United States, for example, ability is valued and as a result "able bodied" people often do not *see* the barriers to movement that exist for people with disabilities. Thus, able bodied people do not *see* the need for ramps that provide accommodations to wheelchairs because they, the able bodied, get around without difficulty. Furthermore, as social beings we learn what to focus on and what to ignore. For example, when a walking person crosses the street they will pay *attention* to traffic signals and ignore whether or not there is a curb cut on the other side. These acts, as Zerubavel (1997) argues, are informed by an individual's social location, similar to location in time and place in the life course perspective. By exploring narratives, I also have the opportunity to examine how people with SCI and their partners *remember* their relationship or how they pay *attention* to specific aspects of the rehabilitation experience.

Tied closely to the act of *remembering*, or memory, is how people construct narratives (Gergen and Gergen 1997; Gergen 1999). Zerubavel (2003) identifies a number of narratives that people use when constructing memories of historical events, progressive, regressive, static, and zigzag. LaRossa and Sinha (2006) elaborate on Zerubavel's conception of narratives by constructing a typology of how the two most basic narratives (progressive and regressive) can take multiple shapes when combined with a retrospective or prospective viewpoint, thus creating four types of narratives: retrospective progressive, retrospective regressive, prospective progressive, and prospective regressive. This is a useful typology for examining narratives

following SCI. For example, patient might say things are worse now (after injury) than they were before, which is an example of a retrospective regressive narrative, or a partner might say they feel their marriage is stronger as a result of the injury, which is an example of a prospective progressive narrative. Furthermore, professionals might use these narratives when working with couples and couples might learn how to pay attention to some aspects of narratives and ignore others. For example, if a patient were to use the above narrative with a counselor, the counselor might respond with something to the effect of "think about all the things you have to be thankful for…you are still alive, you have your partner, you get to see your children graduate, etc." This patient might start to pay attention to the positive aspects of these narratives and adopt them while simultaneously learning to ignore they have lost other functions.

Another relevant aspect of cognitive sociology is the way people create and maintain boundaries, which is tied to the cognitive act of *classification*. According to Zerubavel (1993), classifying is the process of lumping and splitting. Lumping and splitting involves the simultaneous mental act of grouping "like" things together (lumping) and separating different things from one another (splitting). For example, people classify time (e.g., night versus morning), people (e.g., family versus friends), places (work versus home), and life stages (childhood versus adolescence). Through the act of classification we create *islands of meaning*, which results in the creation of boundaries between the two items being classified. For example, we divide older adults and young adults into two different groups. While on the surface this separation might appear to be based on age, it is also based on differences of physical and cognitive functions. In general, young adults tend to be physically stronger than older adults and therefore we assume people within each group would be more similar to one another than they would be across groups. A final piece of classification is that there are multiple ways to classify

things based on the thought communities one is a member of. Continuing with the same example, in the thought community of Americans we think of "old" as 65, the original designated age of retirement in the United States. However, in the thought community of professional football, a player is considered "old" at the age of 30, the age at which performance generally decreases (Moir 2009).

COMBINED PERSPECTIVE

Cognitive sociological concepts complement the life course perspective, especially the constructionist perspectives of the life course. Life course is an excellent tool for examining how individuals experience life events and cognitive sociology is useful for understanding how individuals "think" about this process, especially in the midst of chaos. By using the six cognitive acts and paying special attention to "framing" or "bracketing," I can explore how these acts occur at different points following injury. These two frameworks allow for me to ask questions such as, "Do the events leading up to the injury create a reframing of the injury itself?" Or, "Do the events following injury shape an individual's view of their relationship before the injury?" Furthermore, cognitive sociology and the constructionist perspective rely on the use of narratives to examine how people construct stories of change. These narratives can vary by time (prospective or retrospective), change (progressive, regressive, stability), or a combination (zigzag) (Zerubavel 2003; LaRossa and Sinha 2006). Finally, these theoretical perspectives provided a framework for this qualitative study. The sensitizing concepts from life course perspectives and cognitive sociology served as a starting point for developing the research questions, goals, and analysis.

CHAPTER 4

RESEARCH DESIGN

This dissertation includes data from more than 300 hours of field observations from the rehabilitation center and interactions with professionals and couples, as well as interviews with 18 couples[5] (36 individuals) at three time points. These various data points allowed me to gain a rich and valid understanding of relationship dynamics during the early months following SCI. I chose a qualitative method because qualitative data enable us to know how individuals arrive at meanings, 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). Furthermore, using life course research and treating life events as the building blocks of analyses, we can link individual life events to social structure and changes in the social world (Giele 1998).

Longitudinal. Based on the principles of my two guiding theoretical frameworks, I used a longitudinal design with a mixture of retrospective (looking to the past) and prospective (looking forward) data collection. Scott and Alwin (1998) note that it is preferable, when possible, to collect information about lives at the current moment as people are living them, especially when conducting research using the life course perspective. They also note that using prospective design is very useful in examining change as it occurs as opposed to using memories of the past to construct change. However, even in prospective design most of the data collected is still rooted in the past and present. One potential problem with asking about past events is how we construct memories over time. As Bartlett stated "remembering is a reconstructive process, and

[5] Because of the small number of formal interviews I conducted with rehabilitation professionals, their narratives were not systematically analyzed, but they did inform my analysis of my field notes.

memory inevitably is open to a range of distortions and reinterpretations in the light of subsequent knowledge and experience" (in Scott and Alwin 1998:105). Given my use of cognitive sociology as a guiding framework, I am less interested in examining if a person is telling "the truth." Rather, people construct memories of their past within the context of the thought communities they belong to and being able to talk with people over time helps see how memories this process occurs. How people create memory is tied to the life course perspective and cognitive sociology and has a bearing on the data that I collected. I conducted interviews at three time points; approximately one month post-injury (T1), three months following the first interview (T2), and six months following the first interview (T3). These interview points were guided by the stages of care in the rehabilitation context.

SAMPLING

Recruitment Criteria

I recruited the couples in this research study through purposive sampling using several criteria. First, to be included, one partner had to have sustained a new SCI without cognitive impairment and started inpatient acute therapy no less than one month before our first interview. Persons who had a previous level of impairment that has been affected by surgery or disease were not included. Second, both partners had to be under of the age of 55 at the time of injury. While people do not anticipate SCI in our life course plans, people frequently associate disability with aging. By focusing on younger couples, I was able to explore how couples negotiate and experience a disability that is seen as "off time." While SCI occurs at a higher rate in younger people, the expectations of illness, injury, and caregiving are not associated with youth. In this study, one of my unexpected findings was associated with concerns about aging and caregiving and this is explored in more detail in chapter seven. Because 85 percent of the SCI population

experiences SCI before the age of 50, I initially set my upper limit for recruitment at this age (National Spinal Cord Injury Statistical Center 2009). However, due to some of the obstacles with finding couples who met my criteria, I expanded the criteria to include people to the age of 55 about four months into my data collection. A third recruitment criterion was that they had to be in a committed relationship, which I defined as married and/or cohabiting. While engagement is a symbol and expectation of marriage, I believe many of the relationship strains can be reduced if the partners are not living together. During my data collection, I only had one cohabiting couple, which was in some ways an outlier for this study and I have not included them in the presentation of results at this stage. Finally, I aimed to sample based on characteristics similar to the general population of people with SCI, for example gender, race, and level of injury; however, given the random incidence of SCI, I was able to achieve this goal in some categories and not on others.

Role of Gatekeepers

Before I completed the study proposal, I had a research agreement with the Creekview Center.[6]Creekview is part of the Spinal Cord Injury Model System (SCIMS), which is a national network of medical facilities acknowledged by the U.S. Dept. of Education National Institute on Disability and Rehabilitation Research as having model systems for care delivery to individuals with traumatic spinal cord injury. There are 14 federally funded SCIMS cites in the current cycle and Creekview has been a SCIMS grantee continuously since 1982. It is one of the largest of the current grantees, admits a high number of newly injured patients each year, and follows approximately 600 patients annually at various intervals post discharge.

[6] This and all other names in this document are pseudonyms.

In order to formalize the recruitment at Creekview, I completed Institutional Review Board (IRB) procedures for both Georgia State University and Creekview. Each institution had its own unique IRB process with different levels of concern about study design. There were points during this process that one institution would ask me to change something that would require an amendment with the other institution. For example, one IRB suggested I conduct telephone interviews for safety so that I did not enter a respondent's home while the other IRB would not approve telephone interviews because of concerns for proper consenting procedures. Ultimately, we agreed to ask for consent for telephone interviews at second and third interview points for participants who lived a certain distance from either the university or the center. A second point of difference in the two boards was a concern about my proposed methodology from the Creekview IRB. There was hesitation to approve a qualitative study in which questions might change over time. The solution to this process was to provide the IRB with updated interview guides as they were altered. A final obstacle to data collection and recruitment was the IRB requirement that each spouse must provide consent to the gatekeeper before I could speak with them about the study. This was an agreeable point during the approval process; however, in practice the counselors do not interact with the spouses on a regular basis. As a result, the counselor would introduce the study to potential participants and ask them to share it with their partners at the end of the day and obtain consent and then let the counselor know if they were willing to participate. This scenario resulted in an unnecessary burden on the patient to remember and keep track of the study. With the approval of both IRBs, we changed the procedure so that the counselor only had to gain consent to contact from the patient. Prior to changing the procedure, I did not enroll any couples into study.

Within the Creekview Center, five counselors served as gatekeepers for me (see Appendix A for recruitment materials). I set up a weekly contact schedule with them and a regular time that I was available for meeting with potential participants. I initially planned to do a screening tool with each participant, but since the counselors had access to that information for each patient, together we agreed that they could do the initial screening of potential respondents. I e-mailed all five counselors every Tuesday morning to remind them about the recruitment criteria and my schedule. I was on-site every Tuesday and Thursday from noon to 4:00 pm, and upon request. Introductions were frequently made through the counselor. In some cases I would come to the office during a scheduled counseling time with the patient and other times a counselor would walk with me to the patient's room at an agreed time for an introduction. Usually the counselor would provide me with some background information about cause of injury, age, and general impressions about the patient. In other cases the counselor would provide me with a name, room number, and their schedule and I would introduce myself to the patient. In 16 of 18 cases, initial introductions were to the patient with the partner introduction happening separately or over the telephone. I had at least one referral from every counselor in the center.

Once I introduced myself and explained the study and its requirements to both partners, we set up interview times based on their schedules. In some cases, the counselor would put me on the patient's hospital schedule, which was common practice for research participation in this setting. Consent was obtained at the time of the first interview. Most patients I met were willing to participate in the study, however, there were six times that I met with a couple and they either declined at that time (n=4) or agreed to participate and later declined (n=2). In one case, I met with the couple and they agreed to participate. I interviewed the husband with SCI and on the

day I arrived for the interview with his wife, they found out they were pregnant (unexpectedly) with their second child. She informed me that she could not participate in the study because the thought of dealing with a toddler, a traumatic injury, and morning sickness was already too much. She could not imagine "spending time talking to a stranger about how her life was being rocked upside down." In this case, I sat with her for a minute and I thanked her for her willingness to meet me for the brief moment. Ultimately, I realized the level of emotion work involved in this project for both the participants and for me could be overwhelming. As such, my sample may reflect selection effects because of the level of stability that people must perceive before giving their time to a stranger. Additionally, there is the potential that counselors did not introduce the study to patients they viewed as instable or overwhelmed.

SAMPLE CHARACTERISTICS

This study included 18 couples (36 individuals) at the first interview point. Because of attrition, this study included 16 couples (32 individuals) at the second interview point, and 15 couples (30 individuals) at the third interview point for a total of 98 individual interviews. More information about data collection is in the next section. Table 4.1 presents a summary of couple data. Couples' length of marriage varied from two weeks to 37 years with a mean marriage length of 11.5 years at the time of injury. Most (15) couples had children and ten couples still had children living at home. One couple was trying to have children at the time of the injury. For two couples, this relationship was a second marriage while five couples married their "high school sweetheart" and had never been in another committed relationship other than this one. There was a range in household income at the time of injury, but most couples were above the US median household income for married couples ($61,335).[7]

[7] See Appendix B for a detailed list of couple pseudonyms and individual demographic characteristics.

Beginning with patients, my participants had a fairly even distribution by age with slightly more than half of my sample over the age of 40 (n=11) and less than half under the age of 40 (n=7). Most of the patients were white men, which is close to the general population of

Table 4.1 Couple Demographic Characteristics

	Number	**Percent**
Children at Home		
Yes	10	56
No	8	44
Years Married		
≤5	3	17
6 to 10	8	44
11 to 15	4	22
> 15	3	17
Household Income		
Below US Median	7	39
Above US Median	11	61

people with SCI where men account for 81 percent of new cases. All of the patients in this study had at least a high school diploma and most (n=12) had at least some college. Although most of my couples had household incomes above the median U.S. household income, individually there was a lot of variation. Table 4.2 has complete demographic characteristics for both patients and partners.

Partner demographic characteristics closely mirrored their spouses. In terms of age, just over half of the partners were over the age of 40 (n=10). Most partners were white and female. One interracial couple participated in this study. There were slight educational and income differences among spouses. Unlike patients, two of the partners did not complete high school; however, slightly more partners had some college and there were equal numbers of college graduates. Partner income at the time of injury was skewed toward the lower range, with five partners earning less than $12,500 annually and only two earning more than $50,000 annually.

Level of paid labor force participation varied across time for both the patients and their partners. At our first meeting, all but one of the patients was working full-time in the paid labor force. The one who was not working had taken a medical retirement because of emphysema. At

Table 4.2 Individual Demographic Characteristics

	Patient		**Partner**	
Age	**Number**	**Percent**	**Number**	**Percent**
Under 30	3	22%	4	17%
30 to 39	4	22%	4	22%
40 to 49	9	34%	6	50%
50+	2	27%	4	11%
Race				
Black	2	11%	3	17%
White	16	89%	15	83%
Sex				
Female	2	11%	16	89%
Male	16	89%	2	11%
Education				
Less than HS	0	0%	2	11%
HS	6	33%	3	17%
Some College	5	28%	6	33%
College Grad	7	39%	7	39%
Income				
≤ $12,500	0	0%	5	28%
$12,501 - 25,000	2	11%	3	17%
$25,001-32,000	3	17%	4	22%
$32,501-50,000	3	17%	4	22%
$50,001- 62,500	5	28%	1	5%
$62,501 - 75,000	1	5%	0	0%
$75,001 - 100,000	3	17%	0	0%
>$100,000	1	5%	1	5%

T2, the full time employment rate for partners had dropped to two and the number of patients unemployed rose to seven. Four patients were on a paid leave of absence from their employers and three were working part time. At T3, four patients were employed full time, five were working part time, and six were still unemployed.

Partners also experienced entry into and exit out of the labor force, but with slightly different patterns. At the first interview, only ten partners were working full time, two were working part time, and six were not in the paid labor force. Four of those were stay-at-home parents, one was not working because "she did not care to work," and one was on medical disability. At T2, the number of full time employed partners had gone down to six, while three partners were working part time and one partner was on a leave of absence. At T3, three of the women who were staying home with their children had re-entered the work force for financial reasons, one went to work part time and two went to work full time. Figure 1 provides this information in graphical form.

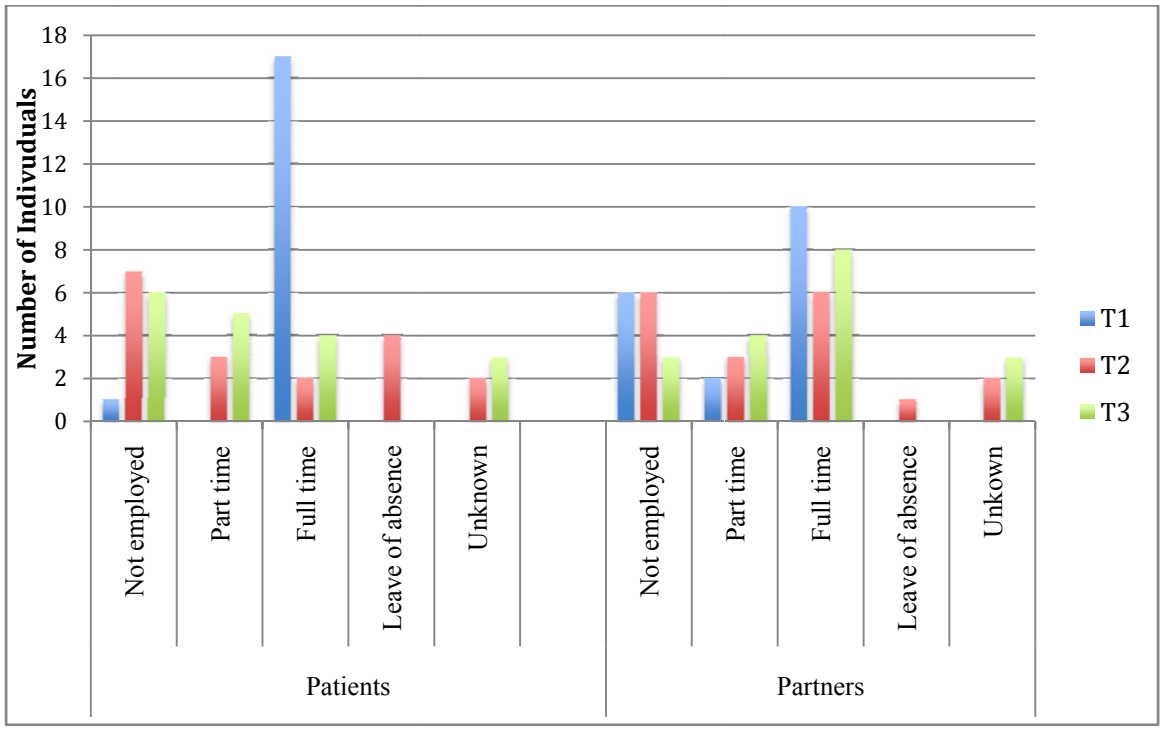


Figure 4.1 Patient and Partner Participation in the Paid Labor Force

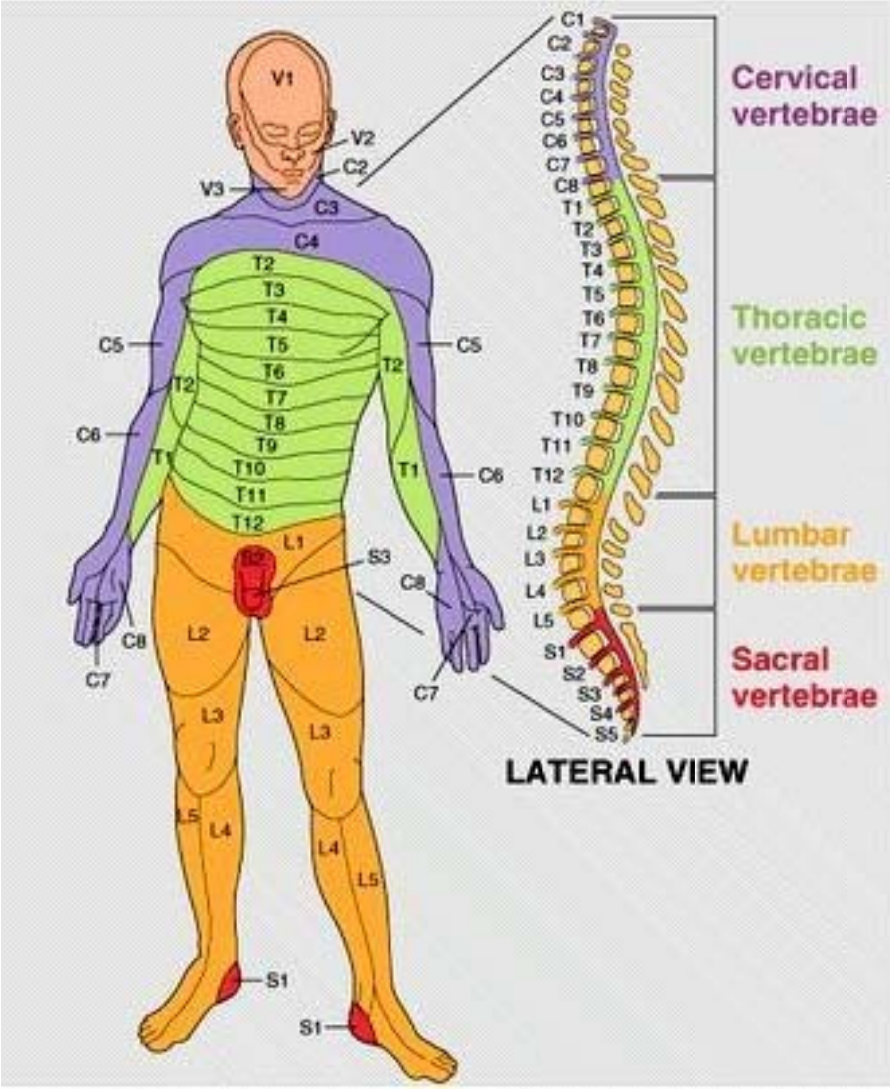
Another key piece of demographic information that was important to understanding people's experiences and transitions to life with SCI was the type and severity of the injury sustained and the cause of the injury. Table 4.3 shows a detailed breakdown of this information.

In terms of injury level and severity, 11 patients had paraplegia and seven had quadriplegia and there were an equal number of patients with complete and incomplete injuries.[8]Although these respondents fell into dichotomous medical categories of paraplegia/quadriplegia and complete/incomplete there was significant variation in the function and ability across these groups. Figure 4.2 provides an image of the areas of the body that are affected by different levels of the spine. Additionally, because of the longitudinal nature of this study, I noticed changes in ability and function over time. There were a number of reasons for SCI, with six resulting from internal causes, such as viral disease or spinal stroke. The remaining 12 patients sustained a SCI from external traumatic events, such as automobile accidents, falls, violence, and work related injuries. I should note that even with illness/disease as a cause, these were sudden onset, unanticipated, and the outcomes mirrored the outcomes of patients with external causes.

Table 4.3 Causes and Severity of Injury

Cause of Injury	Number	Percent
Internal (stroke, viral, abscess)	6	33
Auto	4	22
Fall	2	11
Sport	2	11
Violence	1	6
Work Related	3	17
Severity/Type of Injury	Number	Percent
Complete Quadriplegia	3	17
Complete Paraplegia	6	33
Incomplete Quadriplegia	4	22
Incomplete Paraplegia	5	28

[8] A diagnosis of paraplegia involves damage to the spinal cord at or below the first thoracic vertebra. Paraplegia will typically involve impairment of the lower limbs and potentially the abdomen and chest, but does not involve impairment of the arms or hands. When an injury is sustained above the first thoracic vertebra the diagnosis is quadriplegia and entails some level of paralysis in all four limbs and chest. The severity of an injury is categorized as being incomplete or complete. Incomplete injuries result in movement, sensation, or muscle response below the level of injury. So it is possible, for example, for a person with quadriplegia to walk short distances and for a person with paraplegia to require assistance with coughing due to weak chest muscles.



http://www.sci-recovery.org/sci.htm

Figure 4.2 Image of Spinal Cord and Corresponding Areas of Paralysis

DATA COLLECTION

After I met with a couple and both individuals agreed to participate in the study, I arranged a time to meet with each person individually for the first interview. All T1 interviews were conducted in-person either in the hospital or in a location near the hospital. The first interview occurred approximately one-month after the injury or within one month of entering rehabilitation. In some cases this was longer than one month because of extensive secondary

injuries that required a lengthy stay in ICU. This interview focused on aspects of the couple's relationship before injury and it served as a baseline for examining change and continuity in the relationship over time, as well as to gain an understanding of what they paid *attention* to in the relationship. During this interview I asked questions about how they met, their upbringings, shared activities, and their friends. I also asked them about their daily routines, including division of household labor, before the injury. During our first meeting, I would collect contact information, such as each person's telephone number, address, and an additional contact besides the partner (such as a parent, adult child, or sibling). Although I lost contact with three couples along the way, having multiple points of contact allowed me to stay in touch with most of my respondents. For example, one couple moved between the second and third interview and I was able to locate them through the partner's mother. The first interviews lasted the longest of the three interview points and were 90 minutes on average.

The second interview point roughly corresponded to a transition to an intensive, residential outpatient program and took place approximately three months post-injury. Some people transitioned faster through the process and were living at home at this point, and no person was still in an inpatient status. In most cases these interviews took place near the rehabilitation center or in participants' homes. I conducted telephone interviews with the four participants (two couples) who were living more than two hours from my location. These interviews were the shortest of the three interviews and lasted on average 35 minutes. These interviews were kept short out of consideration for the time of my participants. At this point I focused on events taking place for each individual. I asked questions about family and friend reactions and support. I also focused on daily routines and any points of conflict in the relationship. I concluded each interview with a question about hopes and fears about the future. I

had initially thought that the "reality" of SCI might be salient for individuals at this time point; however, because of the support they were still receiving in the rehabilitation setting it was not as apparent as I predicted.

At approximately six months after our first interview, I met with each individual for the third and final time. All people were living at home, or away from the hospital. Three couples had not been able to return home yet because of necessary and extensive modifications. During this interview, I focused on current dynamics of the relationship. I also inquired about how they felt the relationship has changed or stayed the same over time. Additionally, I asked questions about how they imagine their future relationship. At this point in time, one couple had filed for divorce. In their case, I inquired about: problems in the marriage; why they thought the relationship ended; the event(s) that preceded marital dissolution; and family and friends' reactions. Final interviews lasted on average 45 minutes and were conducted face to face when possible and over the telephone for participants who were living more than two hours away from Atlanta (n=8 individuals).

I interviewed each partner individually, using similar, but slightly different interview guides and questionnaires for both partners. While there are many positive aspects of conducting conjoint interviews, such as generating expanded information and "clarification of differences" (Bennett and McAvity 1985:95), I knew that there would be times, especially when dealing with relationship stress, when it would be better to interview one partner without the presence of the other (LaRossa, Bennett, and Gelles 1981). This method of interviewing was especially important at the third and sixth month post-injury. At times, the non-injured partner expressed feelings of anger and neglect by their partner, but they were not at a point where they wanted to share that information with their partner. As such, I would not have gained information about the

nuanced changes in a relationship if both sides of the couple were trying to maintain a façade of happiness. Additionally, conducting interview separately was advantageous in the case of the couple who divorced. I was able to maintain contact with both partners without adding an additional layer of stress of having them together for an interview or losing them because of the desire to avoid one another.

I was constantly taking notes during this research process. Because I was in the rehabilitation setting two days a week, I frequently took notes about my observations of staff and family members in the hospital. For example, I spent most of my time in the "family lounge" – an area with a number of tables and couches where family members could relax while the patient was attending therapy. I had to opportunity to interact with family members at various stages in the rehabilitation process and to observe how the family support staff interacted with family members who needed assistance. I also observed interactions of my participants and other patients and family members with physicians, nurses, and therapists who entered patient rooms while I was meeting with participants or in public spaces. Additionally, following each interaction with couples and individuals, I wrote field notes about my observations. My notes included details about their home setting if I conducted the interview in the home and their interactions with each other, their children, and health care professionals (body language, conversations, etc.). Additionally, I took notes about the interview experience. These notes were exceptionally helpful at multiple stages in the research process. First, I reviewed them before each subsequent interview to prompt my memory of the topics I wanted to follow-up on. Second, they helped me think about future interviews with new couples because I was aware of questions that were not working well or where I needed additional probes. Third, these notes were extremely helpful during the analysis of data and writing of my findings. For example,

there was one interaction with a physician and a couple that helped me think about the ways boundaries are constructed between patients and their partners. I was in the process of meeting with the couple to explain the study when the physician came in to examine the patient. I stepped into the foyer of the room and the partner asked me not to leave. The physician put gloves on and examined the patient. Meanwhile, the partner was asking questions about wound care. The physician did not acknowledge the partner during this process. After they physician finished checking the wound on the patient, he walked over to the garbage area to remove his gloves and then promptly turned around to the partner and said, "Now, what can I answer?" In this case it was apparent that in this particular setting, and with this particular physician, the boundary between patient and partner was clear and it was demarcated with the donning and removal of gloves. I relied on these notes extensively when thinking about how couples are experiencing this transition and when a partner says she feels alienated from the rehabilitation process, observations like these help make sense of the narratives.

DATA ANALYSIS

I digitally recorded and transcribed each interview and analyzed each transcript using grounded theory analysis (Strauss 1987; Strauss and Corbin 1998). Grounded theory is a "detailed grounding by systematically and intensively analyzing data" (Strauss 1987:22). Grounded theory, as suggested by Strauss and Corbin (1998) allows the researcher to develop theory specifically from the analysis of the data collected. Furthermore, the researcher is able to be critical of his/her analysis, be flexible in the interpretation, to think abstractly, to be sensitive to works and actions as data, and to have a sense of devotion to the process (Strauss and Corbin 1998). The use of grounded theory also can increase the validity of the analysis because of the systematic procedures that are involved.

As indicated by Strauss and Corbin (1998), I initially analyzed data line by line by constantly comparing instances within the data. The focus of the analysis was on "organizing the many ideas which have emerged from the data analysis" (Strauss 1987:23). One guideline for qualitative research is that analysis and data collection should run simultaneously for the time spent on the project. With that in mind, I did my best to transcribe interviews as soon as possible after conducting the interview. However, there were times when my interview points coincided in such a way that I was conducting multiple interviews in a very short period of time. In order to try to keep up with the transcription, I had to arrange for a transcriptionist. Additionally, I would spend some time writing analytical and theoretical memos after reading an interview when there were times that I was not able to do systematic coding because of the large numbers of interviews conducted at specific time points. This practice allowed me to keep sensitizing concepts in mind as I went to additional interviews.

The procedure used to interpret and organize the data is referred to as coding (Strauss and Corbin 1998). Strauss and Corbin (1998) outline three types of coding: open, axial, and selective. Open coding is the unrestricted coding of data (Strauss and Corbin 1998). The data are examined very closely and the goal is to produce concepts that fit the data. Strauss (1987) provides some guidelines for open coding: (1) looking for *in-vivo* codes (words or phrases used by the individuals in the study); (2) assigning a name to the code; (3) asking questions about the analysis; (4) moving to dimensions of a code; and (5) while coding one incident of a category, compare it with the previous incident coded in the same category. It was during open coding that I grouped concepts to create variables. For example, when reading transcripts from partners, I examined statements like, "it is my job to care," "I don't like helping with his bowel functions," and "I'll do what I have to in order to get checked off on the list," which are all indicators of the

variable "types of caregiving." LaRossa (2005) recommended that variable terminology be used in a grounded theoretical analysis, since one of its goals is to generate hypotheses (statements about the relationships between variables).The second level of coding in grounded theory is axial coding, which "consists of intense analysis done around one category at a time" (Strauss 1987:32). During axial coding, it is important that one pays attention to what Glaser (1978) refers to as the six C's (causes, contexts, contingencies, consequences, covariances, and conditions) as they apply to one focal category at a time (LaRossa 2005). For example, when I examined the category "types of caregiving" as a focal category I analyzed how the *context* of this rehabilitation center influenced this category, what previous experiences *caused* the kind of caregiving, what *contingencies* or *conditions* mediated previous experiences and the kind of caregiving, what the outcomes – or *consequences* – of types of caregiving were, and how the category related to (*covariance*) other categories like the intensity of caregiving. Second, one must pay attention to process and people's strategies, tactics, maneuvering, etc (LaRossa 2005). Furthermore, the strategy of generating theory through this process of comparative analysis is central to grounded theory.

Following axial coding, the third step is selective coding. This type of coding involves coding extensively for a core category. To determine which category should serve as the core, Strauss (1987) offered the following suggestions: (1) The core category must be associated with as many other categories as possible; (2) the core category must appear frequently in the data; (3) The core category should not be forced to relate to other categories; and (4) the core category must have clear implications for a more general theory and allow for "maximum variation" to the analysis (Strauss 1987:36). Given the overwhelming amount of data I collected, I had a variety of ways I could examine the data. I examine the aspects of the rehabilitation and subsequent

transitions that were most salient to the participants in this study – the physical and social space, the construction of change narratives, and the negotiation of the caregiving relationship. Because of the variation in each chapter, I discuss specific coding or analysis features that are unique to each core category within each chapter.

Although our discussions of grounded theory often implies that there are distinct beginning and ending points for each phase of coding, in actuality these steps happen simultaneously and the boundaries between them are blurred. I realized early on in my analysis that some variables were more salient than others in the narratives of my participants and began writing theoretical memos about how I thought some items were connected. So although I was not "done" with open coding, I had started examining ways that variables related to one another.

Various approaches to grounded theory apply differing emphasis on induction and deduction from the data (LaRossa 2005). In this study I relied on existing theoretical frameworks of cognitive sociology and life course as guides, and I aimed for a balance of induction and deduction during my analysis. Existing theoretical concepts and my awareness of them allowed to me to engage in what Snow (2004) calls theoretical expansion and refinement. For example, in my findings, I elaborate on LaRossa and Sinha's (2006) typology of transition narratives to include fuzzy narratives, and I refine the typology by including how the medical model of disability shape narratives in a way that is different than other transitions included in the literature.

DATA STORAGE AND MANAGEMENT

Lofland and Lofland (1995) recommend three types of files for qualitative researchers: housekeeping, analytic, and fieldwork. Because of the size and scope of this project, it was necessary to rely on computer files and software. For this study, I created multiple computer files

using a database program. Housekeeping files contained basic information on individual cases (Lofland and Lofland 1995). For each participant, socio-demographic information (i.e., income, education, marital status, and race) and disability status (type, date, and severity) were placed in separate housekeeping files. I kept analytic files, which were theoretical in nature and were organized by conceptual categories (Lofland and Lofland 1995). The fieldwork files documented the actual process of doing research and these files consisted of field notes and memos (Strauss and Corbin 1998). Additionally, I relied on NVivo 8 to manage the large number of codes and files that resulted from the data collection. I had nearly 100 transcripts to manage, varying in length from 14 to 60 pages. I completed open coding by hand on the individual transcript, which was then input into NVivo. I used NVivo to run queries and reports during the axial and selective coding processes.

RELIABILITY AND VALIDITY

The nature of qualitative knowledge and accuracy can vary from the nature of non-qualitative accuracy and knowledge (Rosenblatt and Fischer 1993). Consequently, 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 meanings and accounts of social life from the perspective of those who live it every day (Kirk and Miller 1986). Miles and Huberman (1994) discuss validity in terms of "verification." Verification takes place continuously during the data collection and analysis. When a finding begins to take shape, the researcher confirms or refutes it

in subsequent interviews. Validity checks occur when meanings emerging from data are examined for their plausibility and their conformability.

Reliability is a concept used to measure or test quantitative research, but the idea is used in all kinds of research (Golafshani 2003). However, there are conflicting views about the use of the term reliability 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. On the other hand, 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). In qualitative research, the researcher's consistency and ability affect both the reliability and validity of the study (Golafshani 2003). For example, the inability to conduct interviews and code transcripts consistently might result in less validity.

I used some strategies that qualitative researchers use to strengthen the reliability and validity of a project (Kuzel and Like 1991). First, I engaged in member-checking to the best of my ability. This activity required that I report preliminary findings to participants following data collection. I usually did this at the beginning of the second and third interviews and in some cases after I completed all data collection. I asked respondents for comments. I was usually met with comments like "this is great, I hope I am helping," and I never had a respondent inform me that I was "getting it wrong." There were times when I mentioned my findings and they would ask how they fit into things and if what I was hearing from them was typical. I felt as though they were more concerned about being seen as "helpful" and "normal" and that they did not want

to go against what I proposed. I think in some ways this added accuracy to the project, but in some ways it might have cause a slight increase in social desirability bias among this sample.

Second, I used triangulation (Kuzel and Like 1991) to confirm my research findings. Because I had interviews from patients and their partners as well as some interviews with and observations of practitioners, in effect I had three groups of people who were in a sense experiencing the phenomenon of SCI. Their differing perspectives added a level of understanding to this phenomenon by offering differing views of the seemingly singular experience.

INSIDER/OUTSIDER STATUS

One potential limitation of the validity and reliability of qualitative data depends on the methodological skills, sensitivity, and integrity of the researcher (Guba and Lincoln 1981; Patton 2002). 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. In this study, I had to keep in mind that it was possible that I was attempting to translate my own stance on interview topics into the interaction process. As a researcher, I had to keep my own family experiences with acquired disability in mind, and, while those experiences guide the choice in research topics, I had to ensure that those ideas were not the only ones examined in the course of this study. I had 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 me with an opportunity to obtain richer insights from the collected data and to add an introspective dimension to this research (Cook and Fonow 1986).There were many times that respondents' relied on my personal history as a way to make sense of their own transitions. I had to remind them that my experience might be different, but I

was open to sharing my experience and it created a wonderful bond between me and the participants in this study.

CHAPTER 5:

LIFE AT CREEKVIEW: THE REHABILITATION CENTER EXPERIENCE

During this project I became aware of how much the institution affected patients' and their partners' experiences. Not only during the early months when they spent all their time at Creekview, but as they moved away from the hospital and back into their everyday lives. In this chapter, I provide a basic overview of Creekview and discuss how the medical model of spinal rehabilitation constitutes what Goffman (1961) defines as a "total institution" that has far reaching effects into recovery and partnerships.

Creekview, like many other model centers in the country, has the mission of helping people who experience spinal cord injury "rebuild their lives," to learn to live with injury, and to become as independent as possible. Its goals and mission focus on independence and hope, which I will explore as a central part of the institution as a thought community. Creekview is a specialty hospital, which only treats people with spinal or brain injury. This results in a thought community that focuses on care and recovery unique to spinal and brain injury.

I spent a total of 19 months at Creekview conducting recruitment and observation (See Table 5.1 for a timeline of recruitment and observation). For the first six months, I visited Creekview once a week to touch base with my gatekeepers and to start building relationships with various people in the center. Because recruitment was moving slowly, I chose to spend two days a week at Creekview – Tuesday and Thursday – generally observing in a new family lounge. I arrived at 11:00 a.m. on each of those days and stayed until 3:00 p.m. or 4:00 pm. This served a few purposes. First, I was able to observe families and patients interact in the physical space. Second, I was able to see how some staff members interacted with family members and patients. Third, I was accessible to my gatekeepers if they had a potential participant for me to meet. I

communicated with the five counselors every Monday to remind them about the recruitment criteria and my schedule/availability for the week. This consistency also made scheduling interviews easier. If patients and their partners knew I would be at Creekview every Tuesday and Thursday, we could usually schedule our interview on those dates.

As part of the observation process, I took notes during my time in the field. At the end of every Tuesday or Thursday at Creekview I wrote a summary of the activities that occurred during the day. Some days these notes were very short and not very informative (one page of text). There were many days that I sat in the family lounge and did not see much happening and there were days where I was the only person in the space for three or four hours. Notes from other visits were longer and included more details (2-3 pages). In total, I spent 11 months observing twice a week in addition to observations made when I returned for interviews or to meet patients on days that were not part of my scheduled observation time. The field notes I have from these observations encompass nearly 300 hours of observation and over 600 pages of text. This chapter draws mainly from these observations.

THE PHYSICAL SPACE

Renovations

During my study period, Creekview underwent two large building and renovation projects that changed the spaces within the center. The altered buildings affected a number of daily aspects of social life at Creekview. In this section, I will discuss these building and renovations and how the physical space changed as a result of these projects. Because the building and renovation were occurring when I started recruitment and observation, some of the descriptions of the “old” spaces come from my personal experiences and observations from the time my partner was a patient at Creekview.

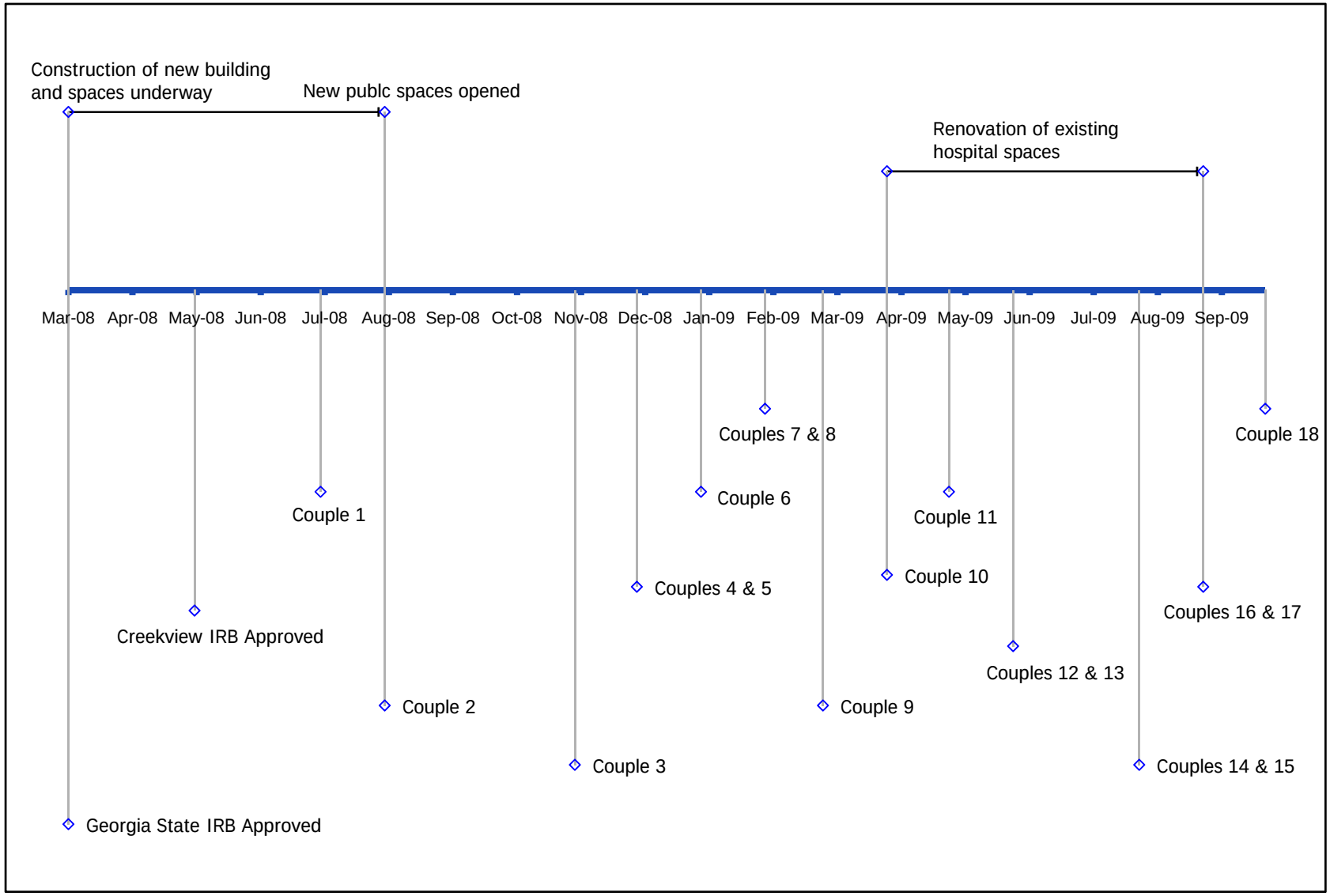
The first major project began in 2007 with a 171,480 square foot expansion of the existing structure to nearly double the space of the facility. The expansion, which cost over $53 million, brought an additional 20 beds, a new café and family lounge, expanded intensive care unit, assistive technology center, more offices and classrooms, more specialty units, larger therapy gyms, a larger cafeteria, and centralized outpatient services. Additionally, Creekview built a new $16 million center that provided temporary housing for families of patients who wanted to stay close to their family member during the rehabilitation stay. The new construction and new spaces were completed around August of 2008.

The second project that occurred during my data collection phase at Creekview was an additional $10-million renovation of existing spaces within the center. This phase of renovation included converting 35,000 square feet of space into new single patient rooms for SCI patients. After the renovations, Creekview increased the number of total beds by 50 – including SCI and Brain Injury Units. Renovations also included new lounges and waiting areas for services in the center. This project began in April of 2009 and was finished in September of the same year.

Patient Rooms

Before Renovation. Prior to renovation, SCI patient rooms were located on two floors of one building, but the majority of patients resided on one floor. When you got off the elevator on the patient floor there was a therapy gym to the left that was frequently full of patients during the day. Straight ahead there was a hallway that contained classrooms and a few offices. To the right there was a large open area with a nurse's station. Patients gathered in the space after therapy in the afternoons and around lunch when there was a break in the schedule. Patient rooms were in

Table 5.1 Recruitment and Construction Timeline



two hallways that, when viewed from above, formed the letter "V" with the nurse's station being at intersection of the two sides.

A majority of the rooms were double occupancy, and about one-third of the rooms accommodated four patients and there were very few individual rooms. Individual rooms were reserved for patients who were under the age of 18 or who required isolation because of contagious infections, such as staph. Rooms were single-sex and because of the limited number of women who were in the center at any given time, most women were given private rooms. Room assignments varied based on patient census, and there was frequently great variety in the demographics of people sharing rooms. For example, one of my participants was white, married, and in his thirties and was sharing a room with two men. One of his roommates was 22 years old and single. The other roommate was around the age of 50, unmarried, and did not speak English. These differences caused friction in the room at times. For example, the older man listened to loud Spanish television and did not respond when his roommates asked him to turn it down, and the younger man sometimes enjoyed "doing donuts" – spinning his power wheelchair in circles at a high speed -- in his power chair in the middle of the room. The couple in my study expressed frustration about not having a private or quiet space and that the "roommates just didn't get it" -- referring to their need to maintain "couple time." However, even with these points of friction this shared space also allowed for some conversation or bonding over the shared experience of injury.

These men, although experiencing injury at different points in life, were all experiencing injury and faced the daily struggles of dressing, bathing, and toileting. And in this case they were doing it in the presence of others. There were nods of agreement when someone went into the bathroom or televisions were turned up a little when curtains were closed and nurses were visiting. There were attempts to allow each other to maintain their dignity as they moved through

this process. For example, one of my male patients detailed a conversation he had with his roommate about the frustrations involved in what used to be simple and taken for granted tasks – like going to the bathroom.

After Renovation. Following the hospital renovations, the setting was markedly different and the experiences of the couples I met before the renovation were different in many ways than the couples I met after the renovation. Following the renovation, patient rooms were still distributed across two floors, but in a different building than before. All patient rooms were single occupancy with a chair that could fold out for a family member to stay overnight. The new rooms had hardwood floors, drapes instead of metal blinds, and large flat screen televisions. While the beds were still hospital beds, they had wood veneer on them and they looked more like a non-hospital bed than they did in the old wing. The hallways and rooms of the new building were quiet in comparison to the old building. When I visited the space, I rarely saw patients talking in rooms. Patients were in their rooms alone, frequently with the lights off. The counselor's offices were spread throughout the hallways and when I went to meet them, there was very little noise in the area.

Partners said they liked the time they could spend with their spouse in the single rooms. They were able to spend more one-on-one time together. The rooms after renovation had a calming feel to them, in part because of the silence in the area, but also there was less tension among roommates and people felt as though they had more control of their surroundings than couples who were in the old building reported.

Public Spaces

Before Renovation. Before the renovation, there were a limited number of public gathering spaces and the hallways and waiting rooms had a very institutional feel to them. The

floor tiles were off-white, the walls were cream and there were brown plastic handrails that ran the length of the hallways. There was artwork hanging throughout the building, most of which was created by current and former patients. These spaces had, in general, a sterile hospital feel to them. When couples wanted to get out of their rooms there were few places to go, and many of the spaces were not very comfortable. Benches in hallways served as private space, yet it was on view for anyone walking down the hall. During the warmer weather months couples frequently spent time in the outdoor spaces attached to the center, which allowed them to find corners and benches away from many people to have conversations or visit with other family members outside of the hospital room. The visits to these outdoor spaces were a point of joy for many patients from early interview periods.

While there were not many private places for people to go when they wanted to be alone, there was a lot of social activity during the daytime and early evening hours. Patients frequently congregated near the nurses' station, which was near the elevators and the therapy gym. Patients would see each other in passing when they were catching the elevator to go to the cafeteria or to and from therapy sessions. Often when passing in the halls, patients would say hi or joke with one another and often "high five" as they passed. Family members also gathered in this space as there was a small coffee machine nearby. Additionally, there was a small "family waiting room" near the elevators that had a telephone, a small television and VCR and two small couches that family members used when they needed a break from the therapy gym. This was a good space for family members to meet one another or to make phone calls.

There was also a patient lounge and library on the main floor of the center. These spaces still exist and are still used by many patients and family members. The library is a small quiet space that has a number of journals and publications about SCI. This can be a useful space for

family members who are trying to understand everything that is involved with SCI. In the early stages of injury with my partner, I spent many hours in this room reading about SCI and ultimately developed the idea for my Master's thesis in this library.

The lounge is quite different from the library. There are a few overstuffed couches, a pool table, and a large television; although I have never seen the television on. Therapists use the pool table as part of a therapeutic recreation therapy program and patients sometimes play pool in the evenings. The lounge still has a fairly sterile feeling to it. The walls are not very decorated and the floors are off-white linoleum, which do not offer much warmth to the room. The lights were turned off in this room many times I visited. The entrance to the garden area is off this room.

Before the renovations there were two primary therapy gyms. One gym treated inpatients and the other treated patients participating in the day program. I did not spend as much time observing the outpatient gym as I spent in the inpatient gym. The inpatient gym was fairly large and had multiple areas with therapy mats – mats at about seat height for easy transferring – as well as standing frames and free weights. There was a set of parallel bars just inside the doors to the right. These were never in use during any of my visits; rather they appeared to be used for storage of large Pilates-type balls. During the day the inpatient gym was busy, but it did not feel crowded and there was always music playing from a portable radio in the middle of the gym.

Physical and occupational therapists worked one-on-one with patients. There could be anywhere between 20 and 30 people in the gym at any given time of day. Physical therapists were very physically involved with their patients – moving, lifting, supporting, or rolling them. The gym had lifts attached to the ceiling to assist with transferring patients in or out of their wheelchairs if they were not able to transfer themselves, but lifts were only used at the beginning or end of a session. During a session, physical therapists would assist patients as they worked on

exercises aimed at gross motor function that would help them accomplish ADLs, such as transferring in and out of their chair or rolling over in bed. Occupational therapists worked on tasks associated with fine motor function, such as eating, brushing teeth, and combing hair. During sessions, patients and therapists remained mostly focused on each other and there was not a lot of talk between patients; however, therapists would frequently talk to one another or to another therapist's patient. Before the renovations, some family members would come for therapy sessions. I saw multiple occasions where a parent or a spouse was used to help with an activity. For example, I wrote the following in a fieldnote:

> Today in the main gym I watched a teenage male play a tug of war game with his mother on Pilates balls. They looked like they were having a great time after a little while. His therapist said she wanted to work on some balance projects with him so he could sit more upright in his chair. I heard him say something about wanting a lower backed wheelchair. The therapist took out two of the large balls and put them on the ground near the mat. She made the boy transfer to the ball and then called "mom" over to sit on the other. She had them lock hands while he tried to pull his mom off her ball and she tried to pull him off. At first the mom was really hesitant and said she didn't want to hurt him. The therapist reassured her that if he fell it would be an exercise to get back up!

Activities were not always as fun or as spontaneous as this particular activity, but having family members in the space allowed for activities like these. There were other times when family members were present to go through training, such as how to take the wheelchair up or down steps or curbs.

Another feature of this space was a kitchen that was fully outfitted for people who use wheelchairs in the back of the gym. The counters were at the proper height, the upper cabinets lowered for easier access, the stove and sink had openings underneath for wheelchair access. This feature of Creekview was good for teaching people how to accomplish cooking tasks and meal preparation when they returned home, however, few of the couples I met could afford the $15,000 to renovate their kitchens to these standards.

After Renovations. The entry of the center now houses a coffee shop that is frequented by patients, visitors, and staff alike. The cafeteria has a large open feel with a covered outdoor eating area. Additionally, there are a number of gathering spaces that did not exist before. There are large waiting rooms for outpatient services with comfortable and warm furnishings, such as leather oversized chairs and floor lamps instead of harsh fluorescent lighting. Waiting areas either have hardwood floors or carpeting. These spaces are filled with patients during the day and are frequently used by families in the early evening hours. The center has also added a large family room to one area of the hospital that includes a wireless internet connection, a small kitchenette with free coffee, tea, and hot chocolate, large couches, tables for working, and computers with a printer. There is also a large flat screen television on one wall and at any hour of the day there is at least one person watching television. Since the renovations, I noted fewer people using the lounge and library than before the renovations.

The hallways on the floors patient rooms are quite different from the other space. When coming off of the elevator there are hallways through a set of double doors to the right and the left. People rarely congregate near the elevators unless they are waiting to get on an elevator. When you enter the hallway to the right (through the double doors) is a large nurses' station. Nurses rarely interacted with me when I entered the space, even when I tried to make conversation. They were frequently focused on paperwork at their desk or talking with one another when I entered. I had the feeling they considered the nurses' station a backstage environment that was separate from the patient and family care that occurred in the patient rooms. The hallways have hardwood floors and are decorated in such a way that, although you know you are in a hospital, it does not have the same sterile feeling. The hallways are long and somewhat confusing. Unlike the old space that consisted of two main hallways, each hallway in

the new space branches off into smaller corridors and reconnects. There have been many times when I have been lost in the patient hallways. Patients or family members do not linger in the hallways. Staff members, such as nurses and nurse technicians, go in and out of rooms, but rarely gathered together in groups. In general these hallways were very quiet.

The two primary therapy gyms (still one inpatient and one outpatient) are much larger than the previous gyms and unlike the previous space patients did not congregate near the gym entrance. Focusing primarily on the inpatient gym, one wall of the new gym area is a series of windows, so the room feels very bright and cheerful on a sunny day. The room still has a number of therapy mats, but there are also treadmills with harnesses for walking training and machines to help people learn balance. These machines take up a lot of the space in the gym, so although the room is larger, it feels small and crowded during a full therapy day. The therapists still keep music playing in the room and, in general, it is a noisy and energetic space. The interaction between patients and therapists is still very similar to the interactions before the renovations; however, there are fewer family members present. I believe this is a function of the crowded space. The previous inpatient gym did not have any treadmills or walking equipment, except the neglected parallel bars and in the current space they take up a great deal of space. Additionally, the treadmills require a number of therapists to get a patient onto and walking. For example, if a person is using the treadmill there will need to be at least three therapists present to assist with set-up, leg movement during walking, and monitoring.

Summary

These renovations have made for a very welcoming and inviting space for patients and their families who are experiencing a traumatic injury, yet it is clear that you are still visiting a hospital environment. There are announcements over the loudspeakers paging doctors or

announcing events in the center and signs about infection and proper hand washing techniques at nearly every turn. Additionally, the corridors are still lined with long handrails, although now they are in natural wood and not plastic.

The physical space of Creekview influenced a number of aspects of social life in the facility. For example, before the renovations, couples were limited in the amount of time they could be alone together. This scenario limited the depth of conversation they could have as well as the level of intimacy they could experience. However, following renovations, couples had more time together when the spouse was in the facility, but patients lost opportunities to socialize with roommates who were experiencing similar transitions. In an interview with one of the counselors, he mentioned that the staff was greatly concerned about the level of social isolation patients were experiencing following the move and were trying to enforce congregate eating in order to offset some of the increased depression they were witnessing.

A TOTAL INSTITUTION

This section illustrates how Creekview functioned as a variation of a *total institution,* which in turn created a unique thought community that all participants of this study became members of. This thought community, which is also part of the larger American thought community, was the context for the analysis presented in chapters six and seven. The first part of this section primarily provides examples and evidence of how Creekview is an example of a total institution.

In addition to the ways the physical space influenced social interactions, the model of care at Creekview also impacted to social experiences of couples as they moved through the rehabilitation process. As I analyzed the field notes and interviews from this project, it was clear that the model that rehabilitation centers are based on continue to meet the criteria of a *total*

institution as defined by Goffman in 1961. Although not as oppressive as the institutions Goffman based his conceptualization on, this institution imposed a great deal of structure for how couples experience the transition to SCI. Additionally, because of the goals of the rehabilitation setting – recovery and a positive future –few participants complained about the levels of control that the center had on their daily lives. This was perhaps because they were attending to other aspects of their experiences such as the type of care they were receiving or their bodily changes. Patients were thankful for the caring staff and the "top-notch" treatment they were getting. Partners, however, focused more on the schedules that were dictated by the staff and appeared to be more aware of the control that the center had on their daily lives.

Goffman's work on prison's and mental institutions were the basis for his concept of a total institution. According to Goffman, a key characteristic of the total institution is the lack of boundaries that separate "work, sleep, and play." Within this setting, work is specified as rehabilitation therapy. Patients and their family members sleep in hospital owned spaces and all recreational activities take place within the Creekview or the immediate surrounding areas. There are four additional criteria for something to be considered a total institution.

The first criterion of a total institution is that "all aspects of life are conducted in the same place under the same single authority" (Goffman 1961:5). During the early phases of injury, the person with SCI resides in the hospital setting. All of their needs are met by the hospital, including food, bedding, and physical care. Outside food is supposed to be cleared by a nurse or physician for fear of causing problems with health or swallowing. Most patients ignore this rule and ask family members to bring outside food in, but they typically do not do this until later in their inpatient stay. The average inpatient stay is two months and very few people leave the hospital for an overnight visit home before their discharge. Upon discharge from inpatient care,

people most often transition to a full-time outpatient program. This program is five days a week, six hours per day. They continue to reside in the hospital setting, but in an apartment attached to and owned by the hospital. At this time they are responsible for all their own care and food. But they still enter the apartments through the hospital, park in the hospital garage and must report o therapy by 8:00 am on weekdays. Although a key feature of a total institution is the complete residential experience, Goffman notes, total institutions are not always physically blocked from entrance and exit, so in this respect, some institutions are more total than others. In this case, the rehabilitation center is more of a total institution for the patient than the partner. Partners have more freedom to move about as they please and they are not under a constant level of surveillance that the patients experience. Therefore, each partner experiences the rehabilitation setting in a different way.

The second criterion of a total institution is that "each phase of the member's daily life is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together" (Goffman 1961:5). Previous literature has highlighted how prevalent this aspect of rehabilitation is; citing that some patients felt the process "was akin to a 'conveyer belt'" (Hammell 2007:261). While none of my participants used this metaphor they indicated they wished they had more privacy, especially before the renovations. However, even with individual sleeping spaces, physical and occupational therapy takes place in a congregate gym setting, with people frequently sharing mat space for stretching. People are grouped together based on age or injury level as they go through their day based on "teams."At Creekview, teams are organized around a medical team that includes a physician (as the lead), counselor, physical and occupational therapist, and a case manager. Teams are typically, although not always, based on diagnosis first and age second. For example, one team has almost

all patients with dual diagnosis (spinal and brain injury) regardless of age. When the population is large enough at Creekview there is also an adolescent program that includes people under the age of 18, and an “older” group that includes people over the age of 50. Patients with dual diagnosis attend additional speech and cognitive therapy. Adolescents spend time working on high school class work as part of their daily program. Additionally, each team has group psychotherapy on a weekly basis and everyone attends courses to learn about various aspects of injury, even if the course module is not pertinent to their injury.

Patients are required to eat lunch together in the therapy gym on a regular, but not daily basis. Before the renovations, patients were given a break from therapy during their lunch hour and could eat lunch in their room or in the cafeteria if they arranged for a meal ticket ahead of time. Since the transition to single rooms, counselors have expressed concern about depression and isolation and pushed for congregate eating in order to provide an opportunity for patients to “bond” and to increase “socialization” among patients. Lunch is brought in on trays from the cafeteria and patients will sit around in a circle to eat. It is a rather social experience with patients chatting with one another during lunch, but they are still eating an environment that does not feel like a dining area. There is exercise equipment nearby and therapy mats and tray tables instead of tables. When eating in the therapy gym, therapists will frequently work in exercises to work on feeding or preparing food, but these exercises are less intense than during a regular therapy session. By making patients stay in the therapy gym during their lunch time, it further reinforces the rigid scheduling of the institution by removing the freedom to eat independent of other patients.

Partners and other family members were also pushed through Creekview in batches, regardless of their differences. This was especially apparent during family training, a series of

courses that family members had to take as part of the rehabilitation process. Each patient had to have at least one person, friend or family, attend these sessions before they were allowed to start making discharge plans. During the course of this study, partners frequently brought up their discomfort or dislike for having to attend these sessions with people whom they viewed as different. For example, two partners whose husbands had started walking before discharge expressed disappointment in having to attend courses that did not pertain to their husbands' injury at all. Most striking was the discomfort spouses had about the discussions of sexual function during this training. Because family training is a multi-day event and sexuality is only one hour of the whole training, the staff members do not separate people by relationship and classes will frequently include parents, children, and spouses. When talking to a nurse educator about this system, she explained that it was "too difficult to separate" people for just one hour of a three day class. Amanda offered the following example of how this caused an uncomfortable dynamic:

> Oh yeah, the sex class was so bad. Of course it didn't help that I'm in the back sobbing like a mad woman. And then we've got a weird mom who wants to know all about her son's new sex life, [just a] very odd dynamic in the classroom. So this poor guy [the counselor] was probably overwhelmed. But it was just like a prescribed, like slide show. And I was like, really? I mean, it was really – I just felt like, I mean, I think I'm pretty savvy. I'll get on the computer and research all day long. I'll talk to people [about sexuality]. But there were wives there who – and they have kids and they may not care about ever having sex again. You know, they might not care…And so I just felt like there were so many opportunities to help people better.

Amanda's excerpt highlights how the desires of the institution to move people through training are not in line with partners' desires to discuss their concerns about sexuality and sexual functioning in an environment that is either individualized or at the very least with people in a similar situation.

Schedules and rules were a big part of daily life at the center. This regimentation is in line with the third criterion of a total institution: "all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time to the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials" (Goffman 1961:5). Within this setting, every Friday afternoon, patients receive a printed schedule of their activities for the following week. They do not have an opportunity to provide input about the times they would like to attend therapy or who their therapist is. Schedules are attached to their wheelchairs and a board in their room. Various therapists and researchers can assign the patient to an activity during the week through a computer scheduling program. For example, on many occasions after a patient agreed to take part in the study their therapist would schedule interview time on their schedule for me in order to prevent that time being taken away by another therapist. Furthermore, because patients are not allowed to leave the hospital freely, they frequently talked about their days being full and packed with therapy, but boring, lonely, and redundant during non-therapy times. One patient captured the frustration of the monotony of the center in the following quote about making a connection with his roommate:

> Me and him [my roommate] went exploring in the wheelchair for the first time and then after therapy we talked about goin', so me and him went down to the cafeteria…it was real nice, me and him to sit across from each other and talk, cuz he's a guy and I'm a guy and we talked a lot about this place, what it's like…that was nice to talk to somebody else and…to get out of the stinking' room and go do something, cuz there's just some stuff that's wearing' on ya, tired of that freaking' speaker goin' off, and tired of nurses comin' on to check, but…get away, just go, ya know?

Although these two men stayed within the hospital setting, the times they could "get away" from their rooms were a welcome relief from their everyday hospital life. Every aspect of their life was under constant surveillance during their inpatient stay. They were woken by nurses, CNAs or physicians every morning, led through a therapy program all day and then continually checked

on by nurses and CNAs in the afternoons and nights. This constant surveillance prevented couples from being intimate or from patients truly relaxing like one would in their own home. This wore on the patients in this study and further limited their level of privacy within this setting.

While patients' daily schedules were dictated by therapy, caregiving dictated partners' daily schedules. Sarah's schedule during her husband's inpatient stay is a good example:

> I get up extra early, stay extra late… I get up at probably 6:00 a.m. and, especially since his therapy's a little bit earlier so I can get over there and help him get his brace on so that he can get up and eat breakfast and get showered, so I get up at 6:00, get over there by 7:00 and we get the brace on, get breakfast, get ready, he'll go to the bathroom and then he'll do shower and then gotta get the brace back off and get everything dried off, get dressed and he gets in his chair and brush teeth and shave and then he goes off to therapy and I'll go wash clothes or straighten up the apartment or call a million people that are callin' to check on him…check a little email myself, read, and then go back and meet him when therapy's over…do lunch, the same things in the afternoon when he goes back to therapy, I'll go, you know, run out and get a couple of groceries or pick up something that he needs, a new shirt, a new pair of shorts, socks, somethin', and then we'll go out and read in the garden together or somethin' or come back to the room, uh, well, sometimes come back to the room, and go eat supper, just hang out…he'll go on the internet, I'll read, whatever, just hang out together and then I'll probably crawl up into bed with him around 8:00 or so, he gets back in…he can't stand the brace anymore, and we'll watch TV until he's ready for me to leave at around 10:30 or 11:00…then I'll go back to the apartment, sleep, and start all over again.

During the inpatient stay, partners' schedules are dictated by patients' schedules, which are dictated by the staff. Sarah's example indicates that the free time she has is spent doing something for her husband's care. Time, as noted by Zerubavel (1979), is possibly one of the most "total" aspects of a "total institution," because patients are always available to other patients and non-patients. Zerubavel's analysis of time and the total institution also examines the relationship between social control and schedules within such institutions.

Finally, the fourth criterion of a total institution is that the "various enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the

institution" (Goffman 1961:5). The aim of the facility is to meet patient rehabilitation goals and daily activities, such as therapy, assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), and counseling, are the main way for this facility to achieve these goals. Staff and administrators pride themselves on meeting patients' needs and for being above the national average for recovery outcomes, such as walking.

Although most of Goffman's writings about total institutions indicate that total institutions are primarily oppressive (Davies 1989), more current writings about institutions show that institutions do not always have to be viewed as oppressive. However, most institutions continue to limit personal freedoms. Goffman proposed a continuum of institutions, which has been expanded on by Davies (1989) and Scott (2010). Along this continuum is the intermediate institution. In intermediate institutions, people can, in principle, come and go from the institution freely, yet in practice they rarely do. For example, at Creekview there are no locks on the doors or fences around the building to prohibit people from leaving; however, the need for assistance during their early stay limits the patients' ability to freely leave the grounds of the center. Furthermore, in all kinds of institutions, there is a clear differentiation of power between people in positions of authority and people who are members of the institution (for training, therapy, education, etc.). This clear difference prevents people from moving between the two worlds of staff and patient. For example, the patients can aspire to become volunteers or peer supporters to help new patients, but they cannot directly become therapists, doctors, or administrators without further education or training.

Furthermore, in intermediate institutions that aim to create some form of change among their members, such as training schools and rehabilitation institutions, there is some level of "stripping away of identity" (Davies 1989:93). This process might be as intense in an

intermediate institution as in a total institution, but the duration is much shorter (Davies 1989). At Creekview, for example, patients are subjected to treatments that are necessary for bodily function, such as a bowel program. For many patients, this ritual involves having a nurse technician (initially) or family member (after training) manually stimulate the bowels by inserting a finger into the rectal area and manually removing feces. This task is done while the patient is in the bed and has no control over the interaction. Keeping in mind the shared living quarters and the social taboos about anal penetration for any reason, this process can be humiliating and frequently strips people of their sense of self for a period of time. As the training and therapy continue, the patient is trained to take over this process as best as they can, but the procedure frequently changes how each partner views the other. Furthermore, the bowel program caused a shift in relationship dynamics from intimate partners to givers and receivers of care. Partners frequently said this was the hardest part of the rehabilitation process. It was difficult to handle feces – the touch and the smell can cause a lot of discomfort – and remain emotionally strong for the patient who is feeling humiliated by the act of having their bowels manually emptied. Following the introduction of the program to partners, each partner wondered if they could ever see each other the same again. There were concerns that the transition to caregiver and receiver might not be reversed to husband and wife again.

NEGOTIATING THE INSTITUTION

Scott (2010) notes, as people move through total and "reinventive institutions" there is the goal of a reinvented self. The reinvented self is not solely constructed by the person undergoing rehabilitation or the experts in the setting, but the interaction between the two (Scott 2010:213). According to Goffman, doctors and other medical professionals hold a great deal of power in determining patients' social outcomes. Identities are reconstructed through the various

"institutional arrangements" of the health care setting because of the unique and restricted world that is created through these patterns of interaction:

> The self, then, can be seen as something that resides in the arrangements prevailing in a social system for its members. The self in this sense is not a property of the person to whom it is attributed, but dwells rather in the pattern of social control that is exerted in connection with the person by himself and those around him. This special kind of institutional arrangement does not so much support the self as constitutes it (Goffman 1961:154).

The physical and social arrangements at the center influenced how patients interacted with their partners. The physical separation between husband and wife allowed the patient to focus on the task at hand, rehabilitation, but excluded the partner from experiencing the positive gains they were making. Practitioners included partners when they saw an instrumental need to do so, for example, helping with caregiving and assistance. Therefore, staff members constructed

While most respondents did not express that their experiences were oppressive or show much concern about power relations, their interactions with physicians and therapists suggested a constant negotiation of power. Negotiations between partners and practitioners included who controlled the amount of time that partners spent together and the amount and speed at which information was presented to family members, partners in particular. Some partners expressed dissatisfaction with being excluded from the daily therapy process. They were asked to stand in a doorway or to only show up on training days. While some partners took this opportunity to have down time and to do other things, other partners felt slighted. As one partner, Cindy, stated:

> She [the therapist] said I could stand at the doorway and watch. And that kind of upset me, because I want to be there to see what kind of progress he's makin' and we're very close and I think it helps him for me to be there…I like to help him and he knows that and I know that, but I was informed that I couldn't come any more and so that, that upset me, especially when he's on the treadmill and I'm not there to watch it and there's another wife in there and she got it on video for me. That kinda upset me…I just feel like I should be able to be in there if I want to be in there…he's my husband…I have the right to see what's goin' on.

Cindy saw her presence during her husband's therapy sessions as a right and did not think she should be excluded, yet she held less power in the relationship and did not feel that she could argue with the therapist. Although Cindy did not know if the other wife was there because of training or her perseverance, she felt slighted. Almost three quarters of the partners in this study mentioned their involvement/exclusion and six partners explicitly stated they felt excluded from the occupational and physical therapy process. Even though partners were upset about being excluded, none of them spoke up to their therapists or case manager, rather they viewed the therapists as the people "who knew best" and complied with their requests.

While practitioners were quick to exclude partners from the daily therapy process they were equally as quick to include them in caregiving tasks, such as rolling patients over in bed and learning proper positioning of pillows, lifting their partner up on curbs, and other tasks they perceived a partner would have to perform in the community. For example, Geraldine said:

> Well, right now, they kind of want you to kind of stay out of the way and that they do it. They tell you to stay back and let them do the stuff, so I've been kinda just trying to stay out of their way, but they're showing me how to – I'm doing stuff like helping him go to the bathroom. We went on an outing, in case we go out, for me to know how to do, how to take care of him like that. Stuff like that. Feeding him, giving him baths, dressing him, shaving him. Doing things like that.

Geraldine was receiving training to help her husband, John, in the community and with ADLs and IADLs. She had been instructed to "stay out of the way" during his everyday therapy program, but she was on-call to learn activities to provide care. In this way, partners are socialized to be caregivers, rather than being invited to be part of the full experience of rehabilitation, such as the first time the patient stands or walks as was highlighted by Cindy in the earlier quote. As members of a dyadic relationship, spouses wanted to share the positive aspects of recovery and excluding the partner from the therapy process in this way strips the identity as partner away from this relationship and places the partner solely in the role of

caregiver. Furthermore, at Creekview, partners, especially female partners, are frequently referred to as caregivers and not as spouses.

Family training was an integral part of the experience at Creekview. During the inpatient stay, partners or other family members had to be "checked off" on certain tasks before the patient was allowed to leave hospital grounds or go home. Partners frequently recounted where they were on "the list." Partners had to be checked off even if the patient was able to perform the tasks on their own. As Cindy said:

> I'm doin' it all, pretty much. I learned the transfers, I've learned the program, the second day I was doin' suppository, a big, that was the program, I can do that, I can do the clears, I've been checked off on that, I'm checked off on dressing, you know, that type of thing…I haven't got checked off on the shower thing, but that'll come soon…he's already done a couple dry runs…wet runs…by himself, and I'm tryin' to think what else, they had to show me…so I mean I'm doin' those, those are the major things…ICs…I've did those and got checked off that afternoon, after I didn't touch anything perfectly, so…but it did, it touched a little piece of the wang, so he was like, you know, he so conscious, you know, 4 rags, and I gotta have wipe this way and wipe that way instead of wipin' it all the way around, you know.

Cindy's itemizing of the tasks she is able to perform was repeated most of the partners in this study. In this excerpt, Cindy is explaining the "clean technique" for performing an Intermittent Catheterization (IC), which is necessary to empty the bladder. According to hospital policy, the person performing the IC must use four washcloths, "two soapy and two clean," followed by a number of systematic steps to keep the area clean, which also means if the catheter touches the penis it is supposed to be thrown away. Based on interviews with these couples and my observations of support groups, most people stop using this technique when they get home because it takes a lot of time and is difficult to do outside of a hospital environment. In fact, by the third interview, no one reported using this technique.

Unlike many transitions into caregiving discussed in the literature (see Walker 1992; Lima et al. 2008) the partners who provided care received a great deal of training before they entered the caregiving role full time. Nancy described the amount of training she received to assist her husband, Sidney:

> They worked [with me] for a couple of days, and I did leg stretches and stuff. And then they had already scheduled me to do family training this week. So I'll be doing that for a class two days, and I have it all day tomorrow. I've just been learning how to do transfers with him onto everything that he could possibility do a transfer on: to and from his bed, and to and from the tub bench, and to and from the car, which is pretty bad. I've been learning all the skin checks and all the padding, just everything.

In addition to the training that occurred in patient rooms and during therapy times, family members attended classroom training to learn about caregiving and SCI, such as checking for pressure sores. These caregiving interactions shape how patients and partners experience their time in the rehabilitation setting.

Negotiations with Others and Other Spaces

In addition to sharing living and therapy space with others, the patients frequently mentioned other patients when discussing their own level of recovery or rehabilitation. They paid attention to how much recovery or family support they were getting in reference to other patients. For example, patients in my study frequently said how they felt "lucky" to have the level of recovery that had because another patient was not recovering as well. Every participant in this study made some reference to "others" at one point or another during this study. Differentiation based on function or family support created a hierarchy of recovery. Starting with function, people with quadriplegia would say, "I am glad I don't have a head injury," and people with paraplegia said, "[I'm] happy I can use my hands." People who had regained the ability walking noted how lucky they were their injury was not permanent as was the case with others.

The process by which divisions are created relies of what Zerubavel (1996:421) refers to as “lumping and splitting” in order to create “islands of meaning.” Within this setting, participants would lump people with similar injuries into one group (i.e. brain injury or paraplegia) while simultaneously ignoring any differences among the levels of variation within each group. People with paraplegia, for example, might all have paralysis of the lower limbs while having different levels of feeling or bladder control, but they were lumped together as “paraplegic.” When lumping like items together, we perceive them being “closer” to each other than they are to other things (Zerubavel 1996). Through this process people create reference groups, or a grouping of people where a people are related in some way and they share norms and values (Shibutani 1955). The reference group then becomes a point of reference when making comparisons to other groups, especially when making judgments about the self (Shibutani 1955).

Splitting, on the other hand, requires people to look at the differences *between* groups, which further reinforce difference. People with paraplegia have use of their arms while people with quadriplegia do not. This difference is reinforced through discourse and action in this setting. People with quadriplegia go through their daily activities together in a different location or setting from people with paraplegia. For example, I watched an occupational therapy group session in one corner of the gym that only included people with quadriplegia playing Uno™ while people with paraplegia were working on free weights in the other area of the gym. People also cognitively create distance between groups by using the spinal column as the location in which the divisions are created. People with injury to one of the six cervical vertebrae are considered quadriplegic, but people who are injured below that point are considered paraplegic. The physical distance between C-6 (lowest cervical vertebrae) and T-1 (highest thoracic

vertebrae) is the same as it is between most other vertebrae, and there might not be any difference in physical functioning between two people with damage at those two vertebrae, yet they belong in different categories and are treated differently as such (See page 37 for a description of the diagnosis of SCI).

The "islands of meaning" that were created within the center shifted when people re-entered the community, either as part of an organized outing or on their own after discharge. This process is tied to the cognitive acts of attending and perceiving, which are filtered through our "social optics" (Zerubavel 1997). Social optics serve as lenses that our experiences are filtered through (Zerubavel 1997). While they were living in the center, people created islands of meaning based on level of injury or recovery. Outside of the center, they belonged to a larger community of wheelchair users or people with disabilities. Participants talked about the center providing protection from the realities of the inaccessible community. One participant referred to the center as a "little sheltered community, cuz they have everybody and things are wider and people are expecting wheelchairs by [the center]." For example, Jesse offered the following narrative during our third interview:

> You know, the big thing for me was, I mean right out of the hospital I came home and the first week or so it was fine, but after that it was kind of downhill because, you know, I guess reality set in and you know, you're in the hospital and you have people to do things for you, but everybody's in a wheelchair. I mean a lot, most people are in a wheelchair, you know and you're not like the only one, but when you, you know, I was home, after that first week or so, and it was like, man, you know, I'm the only one in a wheelchair and I gotta do this, I can do this, but I can't do that kinda thing and uh, it was like really a shock…to cope with that, you know…it was a big, big, big transition goin' on, you know, and thank God, my house was already set up to where I could get around, you know, if it were not accessible, that would have been a big deal.

In this excerpt, Jesse is focusing on the shift from being surrounded by people who use wheelchairs and people who are there to help people who use wheelchairs. This division of able-bodied and disabled was especially clear in narratives from participants after they returned home

or entered the community for the first time. Sarah recalled an outing to the mall with her husband, Phil, in which she started paying attention to the physical spaces around her and to how people interacted with her husband who was using a wheelchair. She said:

> When we went to the mall the other night, you know, you don't really think about certain accessibility things, you don't look at things a certain way…I caught myself watchin' to see how people responded to him…it wasn't weird to be out. I guess if somebody had asked me before the injury if it would be strange to go out with my husband in a wheelchair, if I would feel different about it. It didn't feel different. But I was watching the store clerks to see if they looked him in the eye and responded to him they would have before. That kind of surprised me, cuz I kinda caught myself doin' it. It wasn't something I was consciously doin', I don't know. It crossed my mind that I wanted to make sure that everybody was treating' him just like he was before.

For the first time since her injury she was aware of the division between able bodied and disabled. Leaving the supportive network at Creekview meant a cognitive shift from thinking that wheelchair users are commonplace and spaces are accessible to realizing that there are few wheelchair users and most spaces have a step or narrow doorway they had never noticed before. This is not to say that study participants thought more people in their hometowns used wheelchairs; rather, they had not thought about wheelchair users before their injury and their early exposure was in a supportive location with most people using wheelchairs. As an able-bodied person, few people thought about their physical spaces near or in their homes before their injury because the cognitive act of perception was shaped through the social optics (Zerubavel 1997) of ability and access. Chuck relayed the following story to me about his transition home:

> I couldn't wait to get home. I really couldn't. It was exciting, you know, it was good to be back, but (chuckle), I knew right away that it just, there was just things that just weren't gonna work out you know, with me being in a wheelchair and, I mean I couldn't get into any of my bathrooms. I can get into my master bathroom, but I couldn't get into the toilet. I couldn't get into my second bathroom because my chair [was too big]. I had to go turn this way and then you know, I couldn't just make the turn, and uh, it was so frustrating. It was very frustrating…and still to this day I only have one way I can get out, and that's through a little hallway, into the garage, and out of the garage…man…If no one's home I can't get into my backyard. There's a

> threshold there, and someone has to kinda help me out, so yeah, it's very, very frustrating, you know.

Chuck's enthusiasm for going home was quickly dampened by the spatial constraints in his home. When we spoke at our first interview about his home, he said he would not "need to do much" to go home because it was ranch home without steps and a "wide open floor plan with big doors and a big master bathroom." I visited the home to meet with his wife, Marie, for the first interview and again for their third interview. The home was a very open home, but it had a step into the front door and as his excerpt reveals the doors were not wide enough for a wheelchair. What Chuck and other participants' paid *attention* to before injury was shaped by their experiences as member of the able-bodied *thought community* and it was not until re-entering the physical space that they realized their *memories* of the space were incorrect. Additionally, these excerpts highlight how the *invisibility* of people with disabilities for many Americans further reifies the normality of inaccessible spaces. As Sarah noted, not being a part of the community of wheelchair users means *not noticing* what spaces are accessible and what spaces are not. As people transition into life with injury, their social optics (Zerubavel 1997) shift to include the needs of people with disabilities and there is an increase in the amount of *attention* that is paid to inaccessible spaces.

SUMMARY

In summary, the physical space at Creekview was one factor that directly influenced how patients and partners interacted during their time at the rehabilitation center. Creekview underwent major construction and renovation during my observation and recruitment period and it was clear that the patients and partners I interacted with before the renovations had different experiences than those interviewed following the renovations. The physical space was altered,

which allowed for more opportunities for partners to spend time alone, but less time for socializing with people experiencing SCI.

The four features of a total institution as presented by Goffman (1961) – singular authority; grouped scheduling; regimented days; and a single rational goal – were present in the narratives and field notes collected during the course of this project. The lack of freedom, privacy, and individuality patients and their partners had during their inpatient days affected how partners interacted and how they negotiated their own sense of identity through their rehabilitation process. Interactions with health care professionals stripped partners of their partner identity and placed them in a limited caregiving role. Partners were included in therapy and the patients' daily tasks when it was important or valuable to the therapists, but not if it was valuable to the patient.

Goffman (1961) theorized that within total institutions, there are varying levels of totality based on the institution. Institutions that aim to rehabilitate people, what Scott (2010) called reinventive institutions, are less rigid and could be considered intermediate institutions. Intermediate institutions tend to not be fenced or walled in as a prison might be and the assumption is that one can come and go as they please. While partners had more freedom to come and go from Creekview, patients were limited in their ability to exit without having a staff member or trained caregiver with them at all times.

Additionally, as patients and partners transition through the institution, they are faced with having to negotiate various interactions with practitioners within and others outside of the institution. Within the institution, partners face the constant negotiation of self as partner and self as caregiver. They are pushed into this role through the interactions with the rehabilitation professionals who exclude them from the therapy process and include them in the caregiving

process. Participants also discussed the cognitive negotiations that occurred based on injury level and status. Within Creekview, patients constructed cognitive boundaries between quadriplegia and paraplegia, which shifted to able-bodied/disabled when they interacted with people in the community. Participants expressed a shift in focus to issues of accessibility and the social aspects of disability as they transitioned home and away from the accessibility of Creekview.

CHAPTER 6:

CONSTRUCTING CHANGE NARRATIVES

This chapter focuses on how change narratives are constructed within the context of a rehabilitation setting and the larger community. Based on my analysis, I developed a working model to explain how patients and partners construct change narratives (see Figure 6.1). In this model, I show that there are two variables that influence the direction and intensity of change people perceived – the level of relationship stability at the time of injury and the type and level of injury. I examined data for other categories that might serve as independent variables, such as age, race, class. However, I did not see any meaningful patterns with these categories and the kinds of narratives presented by patients are partners. During my analysis I examined the *causes* of narrative type and was therefore looking at conditions that existed before the entry into the rehabilitation setting.

I used a number of categories to assess *relationship strength and stability*. First, I examined patient and partner narratives about their perception of the relationship, history of tensions, problem resolution, stated strength of the relationship, and stated happiness in the relationship. Next, I examined these two narratives together to look for points of agreement or disagreement. If both partners had high rates of agreement, had lower tension, and higher happiness, then I considered it to be a "strong and stable" relationship. Conversely, if both partners expressed high levels of tension before injury, difficulty resolving conflict, and concern about their future together then I would categorize this relationship as "unstable." I never had two partners agree their relationship was horrible. I did have two couples with high levels of disagreement about past relationship problems and problem resolution. One of these couples divorced during the study period.

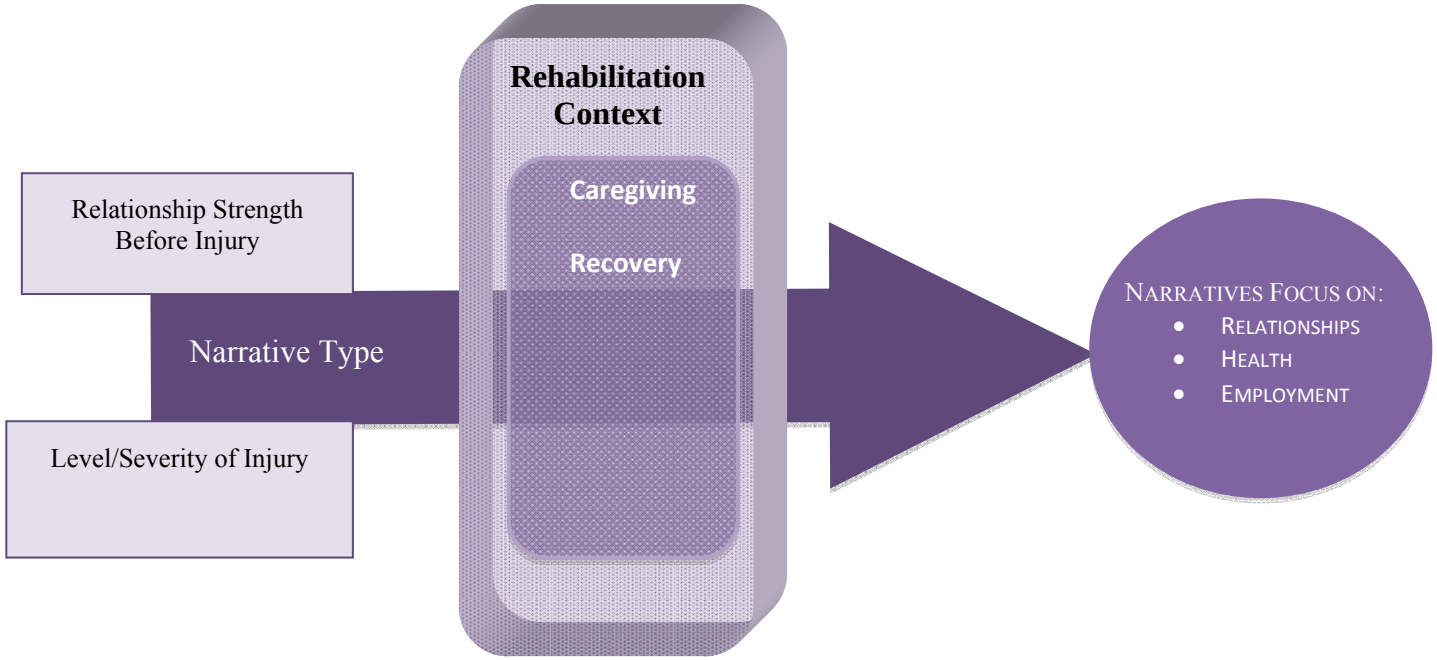


Figure 6.1 Model of Narrative Construction

Initially, I used the patient's medical diagnosis to determine the *type and level of injury* – paraplegia versus quadriplegia and complete versus incomplete. These are further detailed in Chapter Four. The type and level of injury was an independent variable in this model and it had a direct impact on the types of narratives that patients and partners presented. Additionally, the type and level of injury had an impact on level of recovery experienced by the patient. For example, a person who has an incomplete injury is more likely to experience a higher rate of recovery than someone with a complete injury. Furthermore, a person with incomplete quadriplegia will, most likely, experience less return than a person with incomplete paraplegia.

During the analysis of the context of injury, I found that as outlined in the previous chapter, the *rehabilitation* center influenced what patients and partners pay attention to and how their reality is shaped through their everyday interactions with staff members and other patients. Furthermore, the nature of a total institution also creates a thought community of people who are experiencing the same event. Much like the values of independence and self-sufficiency in the American thought community, the mission of Creekview is to "help people with a temporary or permanent disability caused by injury or disease, rebuild their lives with hope, independence and dignity" (Creekview brochure). The emphasis on hope and independence is clear throughout my respondents' narratives. Although I observed therapists explain that independence does not have to mean walking, walking was perceived as an important element of recovery by people in every group that I spoke with during this study. Furthermore, most of the research taking place in the facility by staff researchers[9]focuses lower extremity function. Their website states that "our patients go on to achieve some of the greatest functional improvements from the time they are admitted to the time they are discharged when compared to similar facilities and national

[9] Creekview, like most spinal rehabilitation centers, has a research institute and is continually conducting clinical research with current and former patients.

statistics." Patients who do not experience high levels of functional improvement - especially walking - have the least hopeful narratives, in part because their outcomes are not congruent with the desired outcomes of the thought community.

As couples transitioned through Creekview, they internalized the ideas and goals of the center and these shaped their narratives as they transitioned home. Given the great emphasis on walking and *recovery*, patients who were not able to meet these goals tended to have less positive narratives as the time since injury lengthened. The thought community of recovery and walking is constructed reciprocally from institution to larger society and vice versa. Sensationalized stories of people with paralysis regaining the ability to walk gives patients hope that they will be one of the few that makes a "full recovery." Additionally, the thought community of "Americans" generally values strength, independence, and ability (Nisbett 2003) which are all key facets of the recovery process.

Embedded in the context of the rehabilitation center is the transition into *caregiving*. Within this context, there is an expectation that partners will become caregivers. There are classes that are required for all spouses and potential care providers. Again, the center's website, which is aimed at potential patients, includes a description of the Family/caregiver training goal "to make sure they understand your injury or illness and your needs." There is no mention of caregiver support or self-care. I explore caregiving in more detail in the next chapter. Furthermore, spouses were trained to provide care and this transition into care altered how couples viewed their relationships. Additionally, the levels of giving and receiving care impacted the kinds of narratives presented through the ways that people perceive the burden of care. Patients and partners who perceived caregiving as a burden on the caregiver were more likely to have negative narratives about their future.

When examining what people *focused* on in their narratives, I found they primarily focused on employment, mental and physical health and future relationships and these three foci were frequently interrelated. In terms of employment, the direction of the narrative was shaped by the return of either the patient or the partner to the paid labor force. This variable was more salient for injured men than their wives. Because of the value that paid work has in our society, men who had not returned to work perceived their value as lower in the relationship and expressed higher levels of depression and uncertainty than men who did return to work. Additionally, the relationship between physical and mental health was reciprocal. Patients with poor mental or physical health at the second interview point were less likely to return to work by our third interview, which further contributed to poor mental well-being.

TYPES OF NARRATIVES[10]

This section of the dissertation examines how people assign meaning to their transition to life with SCI. During my analysis I relied on the tenants of cognitive sociology and the constructionist perspective to guide my analysis. With these in mind, I was interested in examining how people moved from one phase of life to another within the Creekview and American thought communities and how these thought communities shaped their biographies. Unlike the social construction of an age category there is a physical division between injury and before injury. However, the meanings that are associated with have an injury are constructed through interactions with others and shaped by our social and cognitive lenses.

The focus of this chapter is how participants used *narratives of change*, my core category, following their injury. These varied by direction (positive, negative, no change) as well as

[10] Every person used each of these narrative types at some point over the course of our interviews. However, I am describing the use of the dominant narrative for participants. So although someone might say they are hopeful at one point in the interview, if their dominant narrative during that particular interview focused on the negative aspects of the injury, then I placed that narrative in a regressive narrative category.

intensity (a lot, a little, etc) and focus (relationship, health, employment). This study expands on Zerubavel's (2003) theory of time narratives and LaRossa and Sinha's (2006) typology of narratives, which presents four directional narratives new parents use when discussing the transition to parenthood.

When examining the narratives of patients and partners using the six cognitive acts, it was apparent that future goals and fears were salient for individuals. Previous literature about transitions has explored the ways that narratives can vary based on time – whether looking forward or looking backward – and based on direction (Gergen and Gergen 1997; Zerubavel 2003; LaRossa and Sinha 2006). Progressive narratives evoke an image that things will be better while regressive indicates a negative change. A stability narrative would indicate little change, while the zigzag narratives are a combination of the previous narratives.

The results from this project, however, suggest there is an additional, fuzzy, narrative in use by patients and partners, which does not imply direction; rather, it implies ambiguity about the future. I should note, that with a few exceptions, when patients and partners talked about the future, they both focused on goals of recovery and the return of function. This emphasis is in part due to belonging in the thought community of rehabilitation, but also belonging to the American thought community that values independence and strength – both physical and emotional. Next, I discuss each of these narratives in turn and how they relate to the previous variables I discussed, especially within the context of this particular thought community.

NARRATIVE TYPES

Progressive Narratives

The progressive narrative indicates that as time goes forward things will be better (See Figure 6.2). Things can be functional changes, relationship strength, motivation, or any number

of items that someone perceives as "bad" at this point in time. At the first interview, all participants used some form of a progressive narrative even if their diagnosis was complete quadriplegia. The injury is new and the hope for recovery is realistic, or at least within reach. For example, Anita (T1) described her husband, Shawn's, diagnosis. She said:

> They say he's complete, but that don't mean he'll be complete, you know. I don't talked to three or four different guys right here in this facility and they been diagnosed as complete and now, they got feelin' back in they stomachs, they can hold they legs, so you know it really is just a matter that the [swelling in the] spinal cord goin' to go down and then they be able to determine more.

As people's experiences were filtered through the interactions with other patients and family members in the rehabilitation center they constructed narratives of hope. All but one person in this study focused on a hope of walking again or at the very least recovering more function than what they or their spouse currently had. This focus on the possibility or reality of recovery and independence pushed these narratives in a positive direction. Anita also highlighted the goals of independence as a way to achieve happiness. She says: "You know, I just hope he can get a little bit more feelin' back so he'll be happy, you know, …cuz I think the more he can do for himself, the less depressed he'll be." Anita's husband had complete quadriplegia and had little use of his arms, yet she still had hope that things would improve.

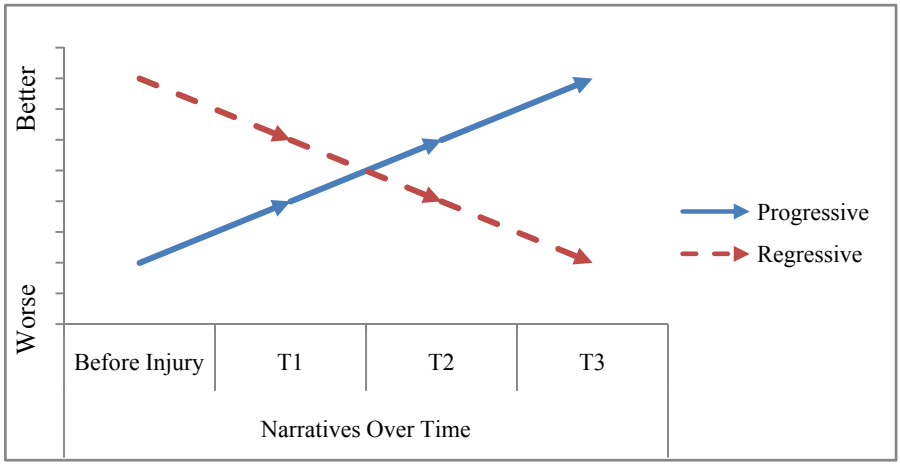


Figure 6.2 Progressive and Regressive Narratives

A second example comes from Cindy (T1, married to Sam for 8 years), whose husband was making remarkable progress when we met for the first time three weeks after he developed a sudden blood clot resulting in incomplete paraplegia, said: "I think because he has made so much progress, that it's just given me a lot of hope and it's kind of helped push me along." Meeting the goal of recovery (frequently in the context of others around them who are not making a recovery) gives people hope that recovery will continue and they will be able to be mentally and physically well.

Sam, Cindy's husband echoed these hopes for a physical recovery. He said: "I hope for a speedy, full recovery! Uh, I know it ain't gonna happen tomorrow, but you know, six months. I'll be fine in six months. I'd like to return to work within a month or two, yeah, I guess a speedy recovery." The focus on recovery as a goal for the future and an anchor on which couples held onto as they moved through the injury process. For example, Marie (Partner married to Chuck) explained her hopes about the future. At our second interview she said:

> My hope, of course, is that Chuck's gonna walk again, you know, and they fitted him with braces last, full braces last week. And if he wears those braces and his knees are locked, with the help of a walker, he can walk. He has to have like the physical therapist walks behind him and hold that belt and blah blahblah. So I don't know if that's what the outcome will be for us, but that's my greatest hope, is that he'll be able to walk again…My concerns? That he won't walk. That's my biggest concern, but I think my hopes out-weigh my concerns.

Although the walking that is occurring at Creekview is laborious and requires extensive assistance, patients and partners alike found solace in knowing there was the possibility that recovery would entail walking. As people transitioned away from Creekview, the heavy emphasis on walking decreased and was replaced with goals of independence, such as being able to shower alone or driving. Ultimately, these progressive narratives about recovery and walking serve as a possible coping mechanism for patients and partners who are transitioning out of a

thought community that emphasizes walking and into a thought community of independence – whatever that might mean to an individual person over time.

Relationship Strength. In addition to presenting progressive narratives about physical recovery, patients and partners indicated they thought their relationships with others would be stronger as a result of the injury. Relationship strength and stability was the second most common topic that patients and partners talked about when they talked about the future. At the first interview point, one partner said she was concerned that it had strengthened their relationship "too much" and they might not be able to stay so happy. Another partner, Marie, said in one interview that "it is kind of eerie how well we still get along." Over and over again, I heard how much this injury "has drawn us closer," and resulted in "learning to love each other more." This perception was especially present at T1 with a decrease in intensity in later interviews, but was still a theoretically saturated concept at T3. All of my respondents talked about relationships in a progressive way at the first interview, but the level and intensity of hopefulness decreased as people transitioned home and other obligations such as work and children reentered their lives.

Patients talked about how the injury had given them a new perspective. The injury caused them to "slow down" and most patients and partners found this refreshing and offered hope for more positive interactions with others in the future. In the following excerpt Jim explained what has been rewarding about this injury. He said:

> Probably slowin' down and just seein' everything and appreciating, you know, other people, other activities, just a whole lot more…before my injury, I was just always go, go, go, runnin' around, runnin' around and now I, you know, I can't do that and so I can, I just think I appreciate…I don't know if it's "life" so much more, but, for sure, other people, you know, a lot more…well, I notice them a lot more than I used to.

Geraldine, a partner (Married to John) said the following during our third interview:

> We realize everything don't have to be done at one time. [John's] had to be slowed down a little bit, but we've been dealin' with it. We've learned to appreciate each other more. It's like every day that goes by, we appreciate each other and everything more than we ever did. We haven't got to take a vacation yet, but we're goin' to.

Being able to slow down and take a break from the hustle and bustle of everyday life helped couples spend time together and reevaluate their priorities. At the first interview point, all patients and partners discussed appreciating this time and the necessity to slow down and not to take things for granted.

Being busy and contributing to society is important for people and experiencing an injury during mid-adulthood can put a sudden halt on one's engagement in the workforce. Refocusing energy toward a family was a meaningful way for couples to think about their future given the tenuous return to the paid work force for many participants at the first interview point.

Partners also stated they thought their role in the relationship might not be taken for granted anymore because of the injury. As Michelle said at our first interview:

> Interviewer: Do you think this injury has affected your relationship in any way…positively or negatively?
>
> Michelle: Oh yeah. I think it's been a big positive, for both of us.
>
> Interviewer: How so?
>
> Michelle: Well, I'm, you know (pause) (Chuckle) I hope that he doesn't, I don't think he will take me for granted anymore, like he, cuz he knows that I've been here for almost two months, and I think it's just brought us closer. Cuz we almost lost him…I guess we'll really see when we go home.

For Michelle, her hope was that this injury, although difficult on many levels, would improve her relationship with her husband and that her assistance to him during the rehabilitation process would change how he treated her when they returned home. Although there is some uncertainty as she approaches the next transition – moving home – she used a progressive narrative to

envision her future. Michelle's narrative also highlights the potential problems associated with an imbalance of power and respect in the household for women. Women's work in the home is invisible and devalued (Calasanti and Slevin 2001) and Michelle hopes that her presence during her husband's injury will change this dynamic when they transfer home. Three partners mentioned that they hoped their role would be recognized at a higher level than it had been before injury.

Although an outlier, one couple said that this injury was helping them transition to marriage. One couple had only been married for two weeks when the husband fell out of a tree while saving her cat. At our second interview, Sarah (partner) said that when looking back this injury was good for their relationship. She said:

> We might not be as close, like we might have had a harder transition. I know that sounds crazy to say, but the movin' in and the livin' together and startin' life together, in some ways it might have been harder, just because we were used to that long distance and no time together and then we would have been thrown in together, but you know, tryin' to…circumstances brought us together and there were no real arguments or anything like that cuz it was all about, you know, just glad to have him, glad things were goin' as well as they were. It gave us time to adjust to the situation before we got back to normal arguments or whatever.

Although the transition to marriage is normative and anticipated, it can still cause a great deal of stress (Boss 1988). Sarah perceived the non-normative and unanticipated transition to SCI as a diversion from the stressors that marriage might have brought her and her husband. Being thrust into the world of SCI, in her opinion, brought her closer to her husband.

Progressive narratives indicate that as people transition into SCI they hope things will get better with time. The use of progressive narratives are intricately tied to the thought community of the rehabilitation institution, but also to the American thought community, which both espouse ideals of hope and promise. Progressive narratives focused on hopes of full recovery and independence, as well as the possibility that the injury would strengthen marital and family ties.

Regressive Narratives

In opposition to progressive narratives, regressive narratives indicate less hope for the future. Progressive narratives were more prevalent during the early months post injury because the thought community of Creekview focused on hope for recovery. As LaRossa and Sinha (2006) noted, educators and the therapeutic setting serve as filters for narrative construction during life transitions. Fewer participants used regressive narratives than progressive narratives. Robert (Partner) provides an example of a regressive narrative. He said: "My worst fear is that [Lisa] doesn't get any better. That she'll be in the wheelchair from now on, and that's hard, because she enjoys cutting the grass, you know." Participants value the return to a walking lifestyle and independence, and the thought community of the rehab setting is one of hope and future gains. In this case, Robert wants to see his wife walk so that she can return to activities she enjoyed before her injury.

Although regressive narratives were less common than progressive ones, at the six-month (T3) interview point there were more regressive narratives than at the earlier time points (n=8 T3; n=5 T2; n=1 T1). These narratives were used by respondents who had lower levels of recovery, perceived lower levels of social support, and had higher levels of uncertainty about future employment. Although people often focused on the physical aspects of recovery, some participants, mainly partners like Brandi (T3, married to Steve for 10 years), focused on the psychological toll that this injury is taking on her and her husband (diagnosed with incomplete paraplegia following a spinal stroke). She says:

> I feel so alone that I'm probably just not the same person I [was], you know, and I feel like I'm complaining and, when I speak to you, I'm like, yeah, this is our life, you know…but, there's no joy… that's what I tell [my friends], I just don't feel like there is any joy in our life.

This is also an example of how narratives are sometimes shaped by looking back to the past. In this excerpt, Brandi is remembering a life with more joy and fun than her current situation. Her husband had a spinal stroke; however, at six months, he has had no significant gains, is still unemployed, and is experiencing severe depression as a result. Their outcomes are not congruent with their hopes for recovery while they were a part of the institution. Now that they are away from the support and encouragement of the center, she feels "alone" and guilty for complaining. Of the 15 couples that I followed for all three time points, the five who were not experiencing any recovery had the most regressive narratives.

Regressive narratives also were tied to other life stressors and feeling overwhelmed. Nancy's husband, Sidney was making strides toward independence at our second interview, but was still primarily dependent on others for assistance around the house, in part because of the inaccessibility of the space and the lack of resources to modify the space. Coming from a family with strong religious underpinnings, Sidney desired a large, traditional family and his wife was overwhelmed by the thought of having more than one child. This scenario resulted in a regressive narrative about her perception of the future of their intimate relationship. When I asked her about sex an intimacy in her marriage, she responded:

> I'm nervous to talk about it. I know he wants to have more children and I'm really nervous about that. I know that it's more difficult now. I've gone through the classes about that, and that's made me upset because we were planning on three at least, and I'm scared to death of having another kid right now because it's hard enough. I mean it's extremely difficult taking care of him and the baby at the same time, and even if he can do a lot of things for himself, it still, I know he doesn't really think about it as much. But when I have her in his room, she's screaming and he's asking me to do something for him in the other ear. And its' like she's whining and I'm trying to take care of her, and he's like, "hey sweetie, will you do this, will you do this, will you do this?" And it's just like nerve wracking, and there's no way I could imagine being pregnant or having a newborn right now. I'm scared about doing a lot of things by myself. I know I won't be by myself, but it just worries me. It worries me that we can't have kids too. That it will be some big ordeal to try

> and just get pregnant or even just be intimate. I know he's scared to death about that, too.

For Nancy, the thought of having another child to care for in addition to the work she was currently doing with an infant and husband who needed assistance was overwhelming. This stress and worry impacted her ability to engage in a sexual relationship with her husband.

Other regressive narratives focused on real and symbolic losses. Unlike Nancy who was frightened of having another child, two other couples in the study mourned the potential loss of a child yet to be conceived. These two couples were in the process of trying to have children at the time of injury and because it can be more difficult for men to have children after SCI, there was a lot of discussion about the what-ifs. Amanda and Derek's story provides a moving example of this loss. Amanda shared with me that although they married young and had been married for 12 Years, they had just started trying to have children. They had been trying to get pregnant for six months when Derek was shot during a robbery. At our first interview, she cried heavily over the loss of a baby that did not yet exist in their world. Although they mourned the loss of Derek's physical functioning, Amanda mourned the loss of the future child with more intensity. At Creekview, a common sentiment among staff was it was a good thing if a young couple did not have children because of the extra stress and Amanda's loss was seen as insignificant. This institutional setting did not give them room to grieve and as such, she experienced a disenfranchised loss (Doka 2002) within the one place that should have comforted her most. At our second interview, she explained that their relationship was going well and she owed a lot of it to counseling they sought before the injury in preparation for raising a family. She said: "We did a lot of work on our relationship before this happened. Kind of preparing ourselves for a family and the stress that that brings and everything. So, instead of a baby, we got a wheelchair." The symbolic loss of a future family caused a great deal of mental distress for Amanda. Six other

respondents also discussed symbolic losses when using regressive narratives, such as worry they might not be able to throw the ball with their child or do work around the house.

An extreme example of a regressive narrative was the idea that paralysis and SCI was a death sentence. Two partners used this extreme narrative type. As one partner said, "I just hope that our life doesn't stop," which summarizes that there was concern among patients and partners that life was going to be worse from here on out. Eddie (Partner) who was married to Brenda was very concerned about his life and relationship after his wife's injury. When I asked what he thought about the future with SCI, he said:

> I thought that's it. There were days there that I thought we was done. Our young'uns - we're not gonna be able to put 'em through college. We're not gonna be able to build a house. All we're gonna do is just have to sit and stare and that's it. Never gonna have no – can't go dancing; we can't go do nothing no more. Honest to God that's the way I felt. I really did. I thought this is just a death sentence for me. I didn't want my children to feel like they had to take care of their mama – to hinder them in any part of their life…I would still like to have a life. I would still like to have a wife that walks. Nothing would tickle me more. To a degree I think it hurts, and it always will hurt us. Will I be able to wholeheartedly, 110 percent accept her exactly like I did? Being honest enough, I don't think I can. I'll always feel…I think she is…It don't matter. I'll always love her, don't get me wrong. I just don't think it'll always – never be exactly like it was.

Eddie's fears about the future were real and honest. Although his narrative was the most descriptive regressive narrative, I think many patients and partners perceive this as their future. However, because of the push to stay positive and hopeful at Creekview, I believe many people did not share this level of fear with me.

Stability Narratives

A third narrative that emerged was a stability narrative (See figure 6.3 for a representation of a stability narrative). This type of narrative was present during the second and third interview points and among patients and partners with high rates of recovery – that is a return to walking.

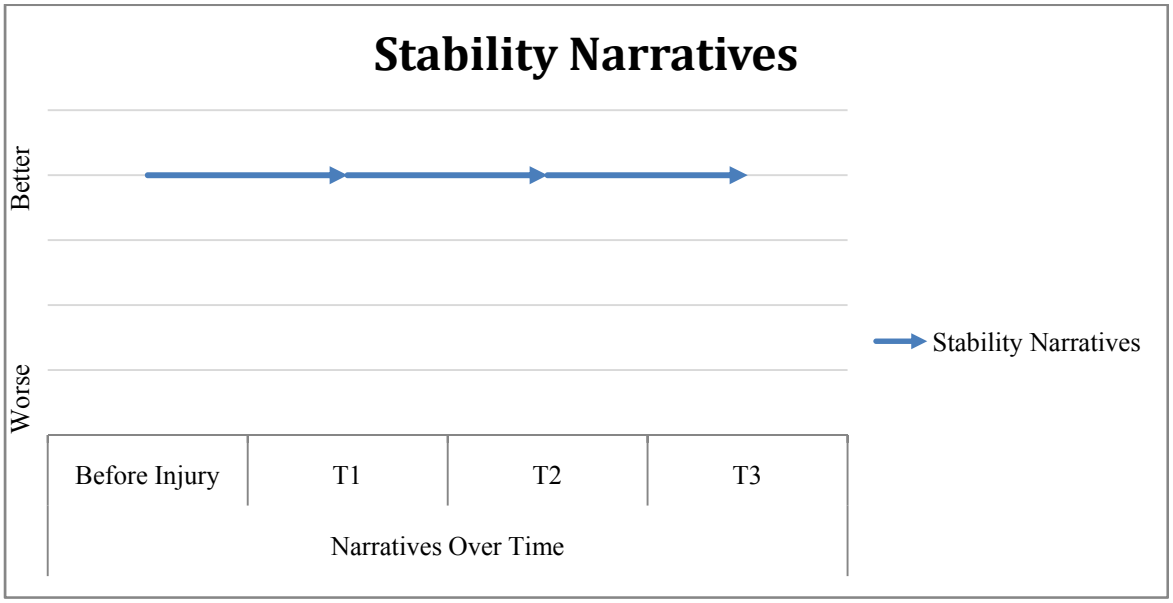


Figure 6.3 Stability Narratives

However, it was one of the least used narratives and only three couples maintained this narrative from the second to third interview point, but about one half of couple used the stability narrative at least one time during our interviews. Although I followed the couples for six months, this time in their lives is still marked by a great period of adjustment and therefore, it was difficult for people to find and focus on stability in their lives. This narrative indicates that although there had been an event in their lives, it had not altered their relationship trajectory. This narrative is closely tied to the act of remembering since it requires remembering the past in order to construct a future narrative. Much like the other narratives that couples constructed following injury, these narratives focused on abstract and individualized concepts. Unlike walking, the feelings in a relationship are not measurable to an outsider. However, many couples perceived little change in their relationships even when the daily routines and expectations had changed. Diane (T2, married to Jack for 12 years) offered the following example when we were talking about her relationship since the injury. She said:

> He's always thanking me for being here, da-da-da and I'll just say, "Well, where else would I be, you know?" It really hasn't been discussed. I mean, I would never think of saying "Oooh you've got this injury, I'm outta here" ya know. We haven't brought it up, we haven't. I guess I know that I'm not gonna leave, I guess he must down inside know that things are gonna, as far as our relationship, we're pretty much gonna stay the same.

Although Diane and Jack have not spoken about the future of their relationship, Diane focused on the past stability of their relationship to explain the possibility for a stable future together. Other participants engaged in more retrospective construction of narratives. For example, Sarah (T2, married to Phil for 2 weeks) said: "[Our relationship is] pretty much about the same…because I think, cuz he's doin' so much better…I think if he was still in a wheelchair, still completely paralyzed, I think it would be different, but no, I think they pretty much stayed the same." She is aware of their exit from the thought community of wheelchair users because of her husband's return to walking after falling out a tree and sustaining a low-level injury. This quick exit from the "disabled" thought community back to an "able-bodied" thought community resulted in her perception that their relationship has stayed the same because they have been able to disengage from the thought community entirely. At the second interview, her husband had returned to work and was no longer engaging in any therapy.

However, in some of these cases, patients recognized that although this injury had not resulted in a change in life trajectory, they sought ways to stay connected the rehabilitation thought community. Two patients who had nearly a full recovery continued to visit internet forums about SCI and read about SCI. They viewed their recovery as a way to "help some people out." Additionally, they spent a great deal of time working out, to the point that one participant referred to his workouts as a second job, to continue to see improvements. In these cases they viewed their personal relationships as not changing, but want to remember the reasons why they have not changed and they wanted to seek ways to help others who were going through the

transition and to maintain their level of recovery. This in turn, could influence newly injured patients in their own narrative construction as they see returning patients making full recoveries. For example, Jack (T3, Married to Diane for 12 years), who had fallen out of a tree and had recovered to the point that he did not require any assistive device to walk at the third interview, said:

> The last three months, everything's been great. The only thing I can say just for me just kind of complacent just I don't want to forget what and where we've been. I just – I feel kind of guilty about it. In my mind, I was like, 'I want to help some people out.' [But] it's kind of hard to find the time.

Jack shared with me that he ultimately did find the time to make a return trip to the rehabilitation center to meet with new patients. His current situation reinforced his positive narrative, because he was a success story. Staff members were complimenting him and showing him off to current patients as an example. Furthermore, during our earlier interviews Jack stressed how much stronger his relationships had become because of the injury and at the third interview he was concerned that his recovery was going to make him become complacent in his relationship as well.

Fuzzy Narratives

Unlike the three previous narrative types, fuzzy narratives indicate a high level of ambiguity and uncertainty about multiple facets of life following injury. As previous research suggests, caregivers and their families do not experience burden as the result of illness, per se, but the uncertainty about the illness and potential recovery. Pauline Boss (1987, 2007) has written and theorized extensively about the experience of ambiguous loss and the effects it has on families. Ambiguous loss can be placed into two categories – physical and psychological. Physical loss involves a physically missing person with psychological presence, including for example, losses through kidnapping or runaway. The person is physically missing, but

psychologically present because there is a chance they might reappear. Psychological loss, which includes brain injury or Alzheimer's disease, involves a physically present body, but a psychological loss (Boss 1999). In many ways SCI is an example of an ambiguous loss because it is not clear what exactly has been lost. Although the person with injury is still physically present, they are present in a different form than before injury and it is not clear what recovery will look like for that individual. I propose fuzzy narratives involve another aspect of ambiguity and trauma put forth by Boss, which has not been studied or developed further – *ambiguous gains*.

Boss (2007) suggested studying ambiguous gains because they also create stress for family members experiencing change. However, in her brief discussion of ambiguous gains, she created a clear boundary between loss and gain as if to say they exist as polar opposites. The findings from this study indicate otherwise. While couples experience loss of a past or potential future, they are also experiencing ambiguous gains relating to the loss. So, while people are aware of a loss of limb movement, they are simultaneously unsure about the gains they might make as they recover. This ambiguity is driven, in part, by the social interactions within the rehabilitation setting and the dominant narrative of recovery. Respondents in this study frequently spoke of life "in transition" or "in limbo," the inability to focus on the future, and the inability to make decisions because of waiting for information from others. Not having a clear idea about recovery time or outcomes created a great deal of ambiguity for couples in this study. This process highlights the way that the Creekview *thought community* in general, and staff members in particular, influence how people construct the transition to injury (LaRossa and Sinha 2006). This was especially clear among respondents with incomplete injuries. Steve provided the following example at our third interview. He said:

> They don't have any, hardly any research or documentation what the outcome can be, so they really don't know what to tell ya. So it's one of those things that, you know, they can't guarantee or anything. They don't know enough about it to tell ya that might not happen or will happen kind of thing. So you know, at this point, I'm kinda frustrated. I'm in that limbo space that I've got to either try to walk or its not gonna be possible then I've got to look forward to making the best I can with bein' in the wheelchair.

Steve's example highlights the fact that the ambiguity about recovery is not only an individual process, but a relational process as well. Doctors and therapists are unwilling to provide concrete outcomes because not every injury is the same, but this interaction further intensifies the feelings of ambiguity for patients and partners.

The expectation of returning home or to work without knowing how that might pan out was also a big concern for people. As Amanda (T2, married to Derek for 12 years) says:

> I mean, when we get home, we get settled, and start figuring out home things and things like that…Right now, its fine; I still feel it's transitional. I plan on having girls' night and *eventually*, I would like to figure out how he can go do his job, how I can go do my job, and we can see each other at the end of the day. I think eventually we will get back to where we have been, but for right now, it is what it is.

Amanda's husband had been injured as the result of a gunshot and his level of injury (incomplete quadriplegia) required them to stay away from their home for over six months while it was being renovated. Their lives were in a constant state of uncertainty during our interviews.

Additionally, the level of responsibility for making decisions and home modifications and alterations rested on the shoulders of the partner, yet, they were unsure of how to go about making these decisions because of the lack of guidance. There was uncertainty about how long they would have in the healthcare setting and what kind of recovery their spouse would have, which affected the kinds of modifications needed. Joan, married to Gary, relayed a story about an interaction with a therapist about the need for guidance with home modifications. She said: "I said, well, just tell me what you think, because I've got to adjust the house…I've got to, you

know, do I need to tear walls out, do I need to…what…I need a little help." The therapist told her they could not give her a concrete answer because things might change as they came closer to their discharge date, but someone would do a home visit soon.

The expectation the spouse will be a caregiver and, in some instances, a loss of that role, left spouses with a period of ambiguity about their relationship. For a period of time their partner relationship has been put on hold and replaced with a caregiving relationship. When the caregiving duties are no longer required, there is uncertainty about what is next. Because the thought community within the rehabilitation center focuses on spouses as caregivers and there are fewer resources to meet caregiver's needs compared to patient's needs, partners can be ill-prepared for this transition. Sarah, who was quoted earlier, said:

> I am back to work…that was probably the toughest part was bein' around him 24/7 for two months and then him gradually goin' back to work and me bein', you know, very excited about that…about the things that he was capable of and that he wanted to get back in to work and then I was stuck with a whole lot of time on my hands, you know, there's plenty to do around the house, but at the same time when you've been carin' for somebody around, well, not necessarily around the clock, but for the most part, around the clock, and then they're gone for a portion of the day, it's like, what, what was my purpose again?

As Sarah's excerpt highlights, when her husband went back to work, she had to remember her purpose in their relationship. Sarah had only been married for two weeks at the time of her husband's injury and they did not live together before they married. The timing of this injury in their relationship created more role ambiguity because they had yet to settle into a married couple relationship.

ZigZag Narratives

One of the great strengths of this study was the ability it provided me to talk to individuals at three time points during this transition. Because of this, I was able to examine how

people construct zigzag narratives, which look into the past as a reference point for what is happening now and in the future (see figure 6.4 for a representation of zigzag narratives). Although I did not need to employ a longitudinal design to examine zigzag narratives, the ability to examine one person's story over time was strengthened through the use of longitudinal data collection. As with many turning points in life, they are not as noticeable in the present, but by attending to certain items in the past one can make sense of the current and future. When examining narratives of my participants over time, every couple had some form of a zigzag narrative, but the directionality of the narratives changed based on recovery or relationship stability.

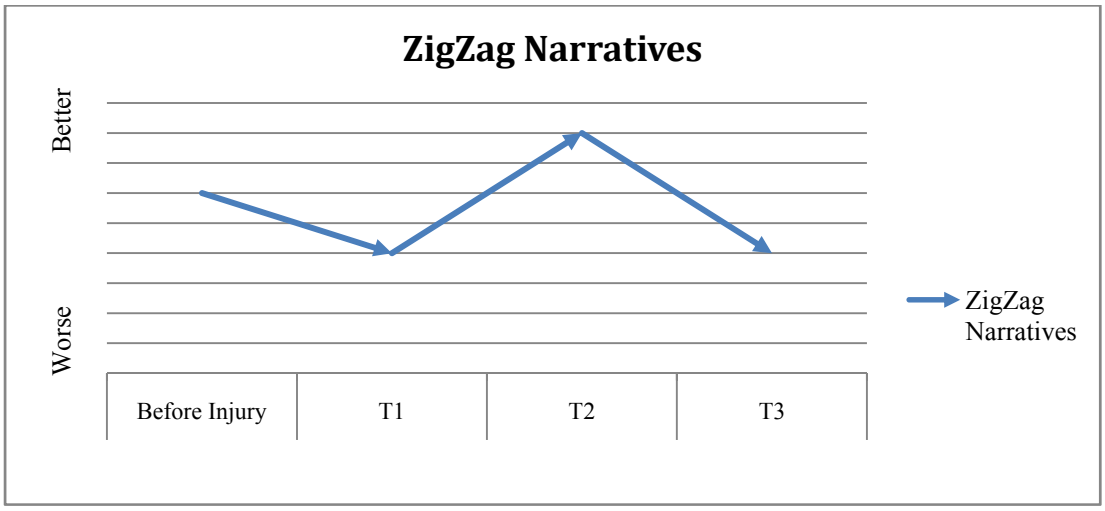


Figure 6.4 ZigZag Narratives

As Amanda noted at our third interview, when looking backward to the early phases of injury she thinks their relationship and her husband's recovery can only get better from here. She said:

> I mean, we've talked a little bit about the recovery process and the way I see it, is we've come through the worst. From here out, it's gonna get better. I'm sure there are things that are going to come up, but that's like with anyone. But this is the worst. I mean, what we've been through already and hopefully from here out, everything gets better.

Amanda and Derek's relationship was very strong before the injury. They had attended couples counseling when they thought they were getting too close and were very supportive of each other. Looking back she thought everything they had experienced for the past three months was the worst thing, and although they did not know what the future will hold, she was pretty sure it would be better than it had been. Additionally, Amanda was linking her experiences to others who had experienced this transition, which indicates that being part of the thought community of traumatic injury rehabilitation provided her with a reference point to base her narrative.

As time passed and recovery status changed or remained stagnant, participants' narratives included more zigzag narratives. This was especially true when the patient was either the primary breadwinner or their roles involved more physical ability than emotional support. In these cases, the focus on returning to work created a progressive narrative while simultaneously remembering a relationship that was good before injury, but was currently difficult. For example, Cindy offered the following example during our second interview. She said:

> I feel like things are getting better. I feel like, I think [he's] stronger. As he's able to work more, he'll kinda take over some of the roles that he used to play in our home and our relationship. And I feel like as that happens then they'll be less pressure on me and maybe I can find myself again. And then maybe we can be closer like we used to be and maybe thing will, you know, get better. And I feel like in the end, we'll be closer than we ever were, but as far as now, it's just…really hard.

Like Amanda, Cindy had a hard time imagining her life could continue in the current state. She paid attention to the positive experiences and the pieces of her husband's recovery that coincided with their respective relationship roles before injury, such as work. Although her focus in this progressive narrative was on recovery, the intensity of recovery had lessened since returning home. The everyday reality of needing a partner that could share in the division of labor and help raise their son was what Cindy focused on in this excerpt.

In the following zigzag narrative, Sydney (incomplete quadriplegia, T3, was married to Nancy for 2 years) highlighted the role that the rehabilitation center had on forming expectations about the transition home and relationships in the following quote:

> You know, they prepared me pretty, fairly well, well really well, for most of the things that I encountered when I got home…but when I got home, after I had the two, two and a half months of counseling, I kinda had this idea in my head that my relationships with people, especially with my wife, I thought they were all going to be better, like improved…I thought that maybe the injury was gonna actually help us in ways, and the thing is, I was so focused on changing, myself and putting forth the extra effort myself, that I never even thought about well maybe other people won't…do the same. I got like tunnel vision, I was only, I was thinkin' of havin' to do this and try this, but…more of my counseling was focused on my reaction to the injury and not so much other people's.

Sydney's focus was on his relationships with his wife and family, which he filtered through the context of recovery. This narrative was constructed through his interactions with the counselors at Creekview. This counseling focused only on the patient and the primary training and counseling for family members is about how to be a caregiver to meet the needs of the person with SCI. By leaving the partner out of the emotional and psychological recovery process, patients and partners could be ill-prepared for the realities once outside of the protective walls of the institution. However, a couple's previous relationship strength influenced this trajectory as well. In this case, the couple married young because of an unplanned pregnancy and pressure from religious parents. This situation, partnered with the one-sided support system of the rehab center, ultimately led to divorce for Sydney and Nancy. This was a unique couple in their situation and the intensity their narratives shifted over the three interviews was greater than any other couple in the study.

SUMMARY

Through the social act of *remembering* we all construct a story of our lives by selectively *focusing* on some events and ignoring others. Our narratives of the future, or narratives of change, are influenced through interactions with other people who serve as reference points. Building on previous research about narrative types and narrative construction during the expected transition to parenthood (Gergen and Gergen 1997; Zerubavel 2003; LaRossa and Sinha 2006), this study examines how people construct narratives during an off-time and unexpected event and how these narratives are filtered through the context of rehabilitation. Before experiencing SCI, couples have various levels of relationship strength and stability and these previous life experiences influence how participants constructed narratives about their past, present, and future. Additionally, the level and severity of the patient's injury also influenced the ways narratives were constructed. At the first interview point, every person in this study presented some form of a progressive narrative, but the level of positivity was mediated by the potential recovery.

As participants moved through the rehabilitation context, I found that the thought community of rehabilitation mediated narratives with the heavy emphasis on recovery for patients and caregiving for partners. The emphasis on physical recovery overrides the needs of couples and partners as they negotiate the physical aspects of SCI and there are times that these two goals at Creekview are at odds with one another. For example, Sydney who focused on his strength and his recovery, assuming relationships would follow along. He thought if he was independent and could be less of a burden then his relationship would be strong again. However, it did not come up in counseling or in therapy that his wife would have needs he would have to attend to as well. Regardless of how much influence the institution has on the construction of

narratives following injury, the institution does not control the direction of the narrative (LaRossa and Sinha 2006). Social research in general and the life course perspective in particular, emphasize the relationship between structure and agency that is present. Therefore, even with the heavy emphasis on recovery or individuality within Creekview, how one made sense of and incorporated these messages into their biography varied by individual.

Both injured and non-injured partners used all of the narrative types that I have presented. The degree to which they relied upon these narratives as they moved forward in the rehabilitation process depended on a number of factors, but primarily was related to their level of recovery and how congruent it was with the mission and goals of the rehabilitation setting. Returning to my model, we see that the type and level of injury, as well as the relationship strength before injury, influenced the kinds of narratives presented. Additionally, the level of recovery and interactions with others in the rehabilitation center influenced the narratives. Participants focused on the future of relationships, the return to work, voluntarily and involuntarily, and their mental and physical health. People with higher rates of recovery had more positive narratives while lower recovery indicated more regressive narratives. Fuzzy narratives were constructed when outcomes were unclear and there was little guidance for partners. Additionally, the investigation of fuzzy narratives is a way to examine the relationship of ambiguous losses and ambiguous gains (Boss 1997) among couples experiencing rapid change.

CHAPTER 7

NEGOTIATING THE CAREGIVING RELATIONSHIP

Care is complicated. Few scholars recognize the paths that people take when entering and exiting informal caregiving relationships and how care recipients and caregivers negotiate everyday caregiving relationships. People who engage in care on a daily basis frequently do not recognize how social institutions, such as hospitals, communities, and places of employment, shape these paths. This oversight is especially true for women who provide care because of the socially constructed division of household labor and the pervasiveness of the cultural expectation of women to be better caregivers (see Hooyman and Gonyea 1995). However, there is a rich history of feminist research that examines the ways that social structures and agency interact with one another during the negotiation of caregiving relationships (see Hooyman and Gonyea 1995; Calasanti and Slevin 2001). In this chapter, I first explore the ways partners enter into caregiving relationships (Aneshensel et al. 1995) and the ways this entry is shaped by individual and structural forces (Acquisition of caregiving). Next, I examine how couples negotiate the caregiving relationship on a daily basis and how they act to create or limit their participation in caregiving spaces (Enactment of caregiving). Finally, I discuss how the negotiation of the caregiving relationship can alter the trajectories for some couples and not for others (Withdrawal/Adjustment of caregiving).

When examining the caregiving relationships among the dyads in this study, few participants were overtly aware of the larger structural forces that shaped their care experiences. This was not surprising because people, in general, often do not see how sociological factors impact their daily lives (Mills 1959). As such, I asked questions of the data like: “How willing are partners to engage in caregiving tasks?” “What are patients paying attention to in regards to

their caregiving relationship?" "What are partners paying attention to during this process?" "Do they draw boundaries about what is acceptable and unacceptable in the caregiving relationship?" and "Are there self-imposed boundaries in care?" Through this questioning process, I found that there were three main types of caregiving relationships – *Naturalized, Constrained, and Resistant* - and these three types resulted in different caregiving careers. Figure 7.1 provides a model of the caregiving career adapted from (Aneshensel et al. 1995) that participants in this study experienced. All three of these groups of caregivers moved along this trajectory. The difference in the experience had to do with the level and intensity of care that was provided at various points along the trajectory and the previous life course experiences they brought into the caregiving relationship. As couples moved through this career, the paths they took and their interactions along the way resulted in differing levels of social readjustment following injury and different relationship outcomes. It should be noted that the types presented in this chapter are ideal types and that the caregiving relationship is constantly negotiated. Additionally, some couples moved between these types at different time points depending on other life factors occurring simultaneously. The numbers I present are based on the dominant type of caregiving style presented in a dyad. A small portion of caregivers was more reticent to engage in care, but willingly did so anyway. At the first interview only one caregiver was extremely reluctant to take on certain caregiving tasks.

NATURALIZED CAREGIVERS

Couples who offered naturalized narratives conceptualized caregiving as a job that had to be done out of love and necessity and as something they were good at providing. All caregivers in this category were women and, as will become more apparent, had internalized the cultural

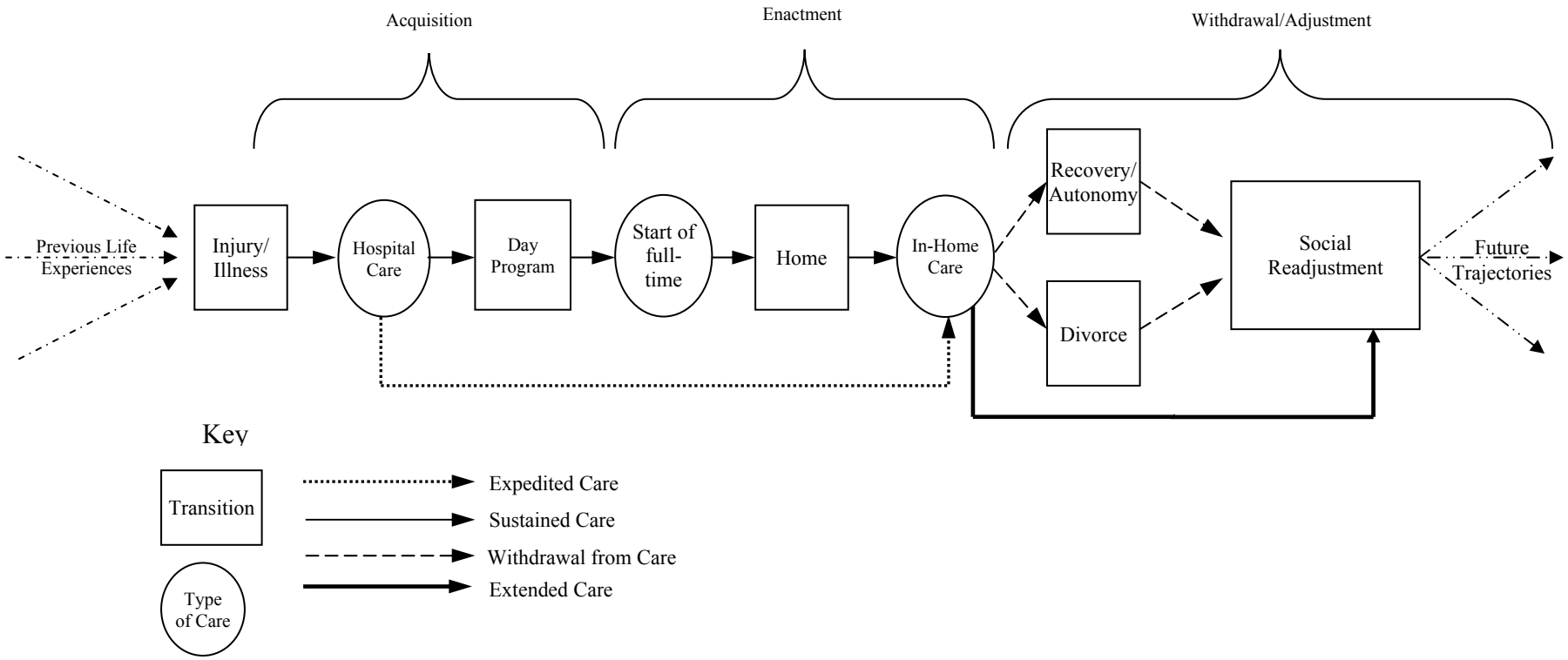


Figure 7.1 Caregiving Careers Following Spinal Cord Injury

Note: Adapted from Aneshensel et al.'s (1995:24) model of caregiving careers

ideals that women are natural caregivers (Hooyman and Gonyea 1995). Caregivers in this category neglected their own emotional and physical health in order to accomplish caregiving tasks. Calasanti and Slevin (2001) noted that women suffer more chronic health problems as a result of their higher levels of care work. Because of their attention to illness or injury, naturalized caregivers engaged in higher levels of surveillance of their partners than did caregivers in the constrained or resistant categories. Because of the heightened level of surveillance and control caregivers in this category had, care recipients had lower levels of autonomy than the other two groups. Naturalized couples (n=6) consisted of mostly patients with quadriplegia (n=4) and tended to have longer marriages (mean=15 years). Partners in this category tended to have less education (less than high school to some college) and earn the least amount of money (modal category = less than $12,500). Patients in this category also had lower levels of education (only one patient was a college graduate) and earned, on average, at least twice what their partner earned. All African American participants in this study also fit within this category.[11]

Naturalized caregivers could be characterized as willing to do what needed to be done in order for their partner to be safe, comfortable, and happy. Many caregivers in this category, especially those with few social resources, had previous experiences with caring for other family members. This was more likely for women who had fewer social resources. For example, Geraldine cared for multiple family members and Anita cared for her mother-in-law who had experienced a stroke. These previous caregiving relationships made entry into a new caregiving relationship a fairly smooth transition. Previous research has shown that lower class women are pushed into caregiving earlier and faster than women with social resources to purchase social

[11] Although the African American respondents were all in the category, I did not see differences in their narratives when compared with white participants. Other structural factors such as income and education had a larger bearing on their caregiving trajectories than race.

supports on the open market (Armstrong and Armstrong 2004). For example, Anita was pushed into providing care for her mother-in-law after her sister-in-law abandoned the family during the time of crisis. Anita explained:

> And see, his Momma, she had a stroke and Momma do everything for [his sister] and her 2 kids, and den when his Momma had a stroke and [his sister] ain't no help her and was nowhere to be found…did not come around whole time or nothin', so me bein' the person I am, I went over there every day, me and [my husband], and my daughter and we cleaned up, I took her bath, I, you know, my daughter was washin' her legs, I cooked for her, cleaned up the house and I did that for about 5 months after her stroke

Anita perceived her entry into the caregiving relationship as the result of the kind of person she is, meaning caring and helpful, while simultaneously not recognizing how her social location – poor, rural, female – appeared to push her into this caregiving role. Furthermore, her daughter, at the age of eight also was recruited to provide unpaid care for her family member. Anita's reliance on her daughter was unusual in this group of caregivers, but it speaks to the transmission of care work as women's work from mother to daughter. Because of the invisibility of care and the pervasiveness of caring as women's work, many women have internalized the message that women are natural caregivers (Aronson 1992). However, in this study and previous literature, women's narratives also reflect the lack of choice that women who provide care are faced with (Hooyman and Gonyea 1995). This and similar experiences with caregiving allowed some women in this study to slide right into a new caregiving role without hesitation or questioning. Again, Anita provided a good example:

> Interviewer: Are there things that you're nervous about doing in terms of medical care?
>
> Anita: Mmmhmm [No]
>
> Interviewer: Or that you don't want to do?
>
> Anita: Nah, if I gotta do it, I gotta do it.

For partners in this category, care is something you just "gotta do." As Calasanti (2006:272) has pointed out, carework entails dealing with all the "negativities of the body – shit, vomit, sputum – all the aspects of the unbounded body." The fact that the women in this category were willing to take these tasks on does not take away from the fact that caring is physical and dirty work.

The women in the naturalized category suggested that care should not make you squeamish or angry, but that could occasionally cause a higher level of stress. Partners expressed feeling stressed about caregiving when discussing the move home, especially if they made a trip home to start the process before their partner was discharged. As Cindy offered in the following excerpt:

> There will be the housework that he doesn't get done and the kids and, you know, it'll still be, it's just gonna be crazy…everything I've been doin' now, plus, you know, um…I went home last night…I really started getting stressed, you know, yeah…thinking of what's to come…I'm just really stressed, but I just have to DO it, this is what has to be done at this point, so that's what I'm prepared to do.

Cindy lived across the street from her parents and she did not ask them for help with housework or with her children. She expected her husband would not start doing these things because the unstated agreement in their relationship was that she bore the responsibility for the second-shift (Hochschild 1989) work in the home. The responsibility for care fell on her and she perceived this responsibility as something she just has to do – in addition to caring for the children, the home, and since her husband's injury, a job. Although the relationship dynamics have shifted and Cindy had to re-enter the labor force to pay the bills, she did not ask her husband to manage the second-shift at home. Unlike the couples in Hochschild's (1989) classic analysis of housework and childcare, the former breadwinner in these relationships was frequently viewed as physically unable to provide the care. However, the negotiations about housework and childcare did not occur in the early months following injury.

Anita and others in this category moved quickly into caregiving and were the initiators of entering the caregiving relationship. During my second interview with Shirley, she spoke about her entry into caregiving. She said: "I was always there to learn, you know, they didn't have to ask me, I did it on my own, you know…I'll asked 'em this and that, and so they would, you know, they would show me and stuff." Shirley, who is married to Jim, was eager to learn about the caregiving process and all that it entailed. Like Anita, and most of the women in this category, Shirley did not work when her husband was injured and perceived the caregiving relationship as an extension of the unpaid labor she already provided in their household.

All partners in this category willingly moved into a caregiving role, but for some this has been their first experience providing semi-skilled care to a family member. I refer to care in this situation as semi-skilled care because there is some training involved in the caregiving process, but it does not require specialized skills, such as administering an IV. The training and classes at Creekview could be considered an orientation into caregiving for partners and family members. Partners in this category frequently referred to their caregiving as "a job" or "work." As Shirley said:

> I went to the class yesterday, what I have to do for Jim, what he's gonna go through and stuff. But it was an eye-opener. It's was like, you know, my work is cut out for me. But I know most of it Jim has to do. He's gonna be able to handle it, but I know I have to be there for him. And it doesn't bother me. I tell Jim to just focus on getting well. Let me handle it, you know, take of everything.

Shirley's goal was to be the rock for her husband. Like other naturalized caregivers, she wanted her spouse to be able to focus fully on recovery and let all the caregiving tasks fall to them. As Hooyman and Gonyea (1995) noted, caregiving is often viewed as a personal relationship between two people. However, that relationship cannot be separated from the various policies and structures supporting that relationship.

Naturalized caregivers took the task of caregiving seriously and worked diligently at being good workers. As shown in the previous chapter and supported by existing literature (see Yee and Schulz 2000), it is difficult to maintain this high level of care and support before one or both members of the dyad experience poor health outcomes. In Shirley's case, she started to experience physical pain and burnout at later interview points. The work that partners did was strenuous, tiring, and at times slightly repulsive. However, they continued with their dedication and determination to be a good caregiver. In the following excerpt Shirley explained one of the most difficult aspects of transitioning into caregiving:

Interviewer: What do you think has been the most challenging for you?

Shirley: Um, well, believe it or not, with the bowel program, you know?

Interviewer: I believe it.

Shirley: Yeah, that, you know…even though I've gotten used to it and stuff, and I know how he feels, cuz sometimes you feel so bad…he says all I do is poop. I said, well, that's just part of you. I said, don't let this bother you, you know, and I help him out. I know he feels bad I can see it in his eyes, and I just try, I said, Jim, this is just part of the job. I said, don't worry about me…I've gotten used to it, cuz at the beginning, the very first, when I had to be there, at Creekview, and I'm not gonna, I'm gonna gag, you know, but now it don't faze me anymore. I help him clean up, you know…I just want to make sure he's clean. He feels bad, you know, cuz he's like, I'm sorry…don't apologize, you don't have to apologize to me, you know

For Shirley, providing this level of care was "just part of the job." Shirley put aside her discomfort with bowel care to ease her husband's discomfort with the process. She turned her unpaid caregiving into a full-time job that removed the human emotion from the caregiving relationship.

Perceiving the caregiving relationship as a job was not only done by partners, but by patients as well. Patients in this category perceived the care their partner provided as a substitute

for employment. Jim, Shirley's husband, described how Creekview's policies shaped the caregiving relationship, which ultimately gave his wife "something to do." He said:

> No, they absolutely were wonderful…when I was in the hospital, Shirley was encouraged to come, encouraged to learn everything she could and they do that for everybody, whether it's mother/child, father/child, spouse, boyfriend, girlfriend…they encourage…I've seen it, you know. Shirley loved it and it's really strange…it just has given her something to do, or given her a job, you know. Prior to this, she didn't have a job and so she really has…I think it's good for her.

Most of the patients in this category did not question the encouragement their partners received to become caregivers. They did not question the structures of their lives before injury that would cause some partners to feel as though they did not have a purpose in the relationship. Like the women in this category, these men had internalized the cultural ideal that women are caregivers and would naturally assume this role. These ideas about natural gender roles further reinforce gender inequality in the home. For patients in this category, care was something their partners were supposed to provide. Some patients in this category recognized the power the rehabilitation institution had on constructing the caregiving relationship, yet were still unaware of the unequal balance of power in their own home. As John, who has been married to Geraldine for 37 years, said:

> They kinda, to me, a little bit, kinda took advantage of that she was doin' for us…like the lady in the room with us, her husband was almost completely paralyzed, but she wouldn't step in and do their job for 'em, but Geraldine would…but it wasn't because they wanted her to do it, she wanted to do it, you know…but she's just that way…Geraldine's like, I mean she's not gonna set back and just watch somebody do somethin'…but then they would kinda, you know, they'd say, oh, your wife's here, so they'd go into another room, you know…but she wanted to do it, too…so she helped take a lot off 'em…but I loved for her to do it, too (chuckle).

John wanted his wife to care for him. He, like most people, would have preferred to have the person they are closest to and have the most intimate bonds with caring for their daily needs. A married person will almost always turn their spouse first for care regardless of whether the

spouse is male or female (Kaye and Applegate 1990). However, this expectation and willingness to have the spouse provide care while in the rehabilitation setting creates fuzzy boundaries between who is staff and who is family.

Nurses and aides were quick to bring family into everyday caregiving tasks, as discussed in chapter five, but over time, partners could become so immersed in hospital care that nurses relied on naturalized caregivers to provide all the care and partners perceived their own role as equal to nurses and aides. Shirley provided a good example of this off-loading of care in the following excerpt:

> Then one of the [nurses] kept sayin' when she was comin' when Jim called for help, she would direct it to me like I wasn't doin' anything, and I said, "I always help out in here, whenever the nurse come in, I help out," you know…I guess the way I said it, she like, got her act together, cuz she was like, "well, did you do this to help him out"… and I'm like, "I said I was told I can't lift him…somebody has to be here before I get him to do anything," you know, so I kinda straightened her out and she like…you know, she backed down.

Two key things are worth highlighting in this interaction. First, this excerpt examines the how Shirley negotiated her transition into the caregiving role. Staff members at Creekview were pushing her into the role of caregiver and when she did not engage in care work on her own, the nurse confronted Shirley and treated her like a member of the nursing staff that is failing to do her job. Second, Shirley's response to the nurse was confrontational, which "straighten[ed]" the nurse out. Shirley perceived her role to be equal to the paid employee, which gave her the right to speak her mind about who should provide care.

Emotion Work among Naturalized Caregivers

As people moved along the caregiving career, every person in this study engaged in emotion work to some extent. Emotion work, according to Hochschild (1983:7), "requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper

state of mind in others". Hochschild's concept of emotion work builds on Goffman's (1959) theories of dramaturgical emotion and impression management. These theories stress the idea that emotion is socially and culturally shaped and scripted. While Goffman's work recognizes the social construction of emotions, Hochschild emphasizes that people work to maintain a socially and culturally correct presentation of emotion. Within families, social actors engage in emotion work to maintain emotional balance in the home. However, much like care, women tend to engage in more emotion work in families than men (Hochschild 1983). Although everyone in this study engaged in some level of emotion work, partners in the naturalized category tended to engage in emotion work more often than couples in the other two groups. In the first few months following injury, emotion work frequently began as a form of reassurance. This included reassurance about having a strong relationship, sticking through the injury, and general "love." Anita provided a good example in the following excerpt:

> I say you know my family love you jes like you one of us. I say 'you ain't got to worry about, about bein' bored, or nothin' like that because you gonna be taken care of'…I think he might of felt because he was [injured] that I probably leave him or somethin', you know what I'm sayin' and because he said 'I might not tell you how much I love you every day, but you know I love you and I there's nothin' I wouldn't do for y'all,' and I said 'you know we love you, we gone be right here for you, anything you need, we gone be right here for you, we ain't goin' nowhere,' you know, so I just try to let him know, cuz I don't want him to fall into a depression, you know what I'm sayin'?

Anita's husband, Shawn, wanted to reassure his wife that he loved her and was more vocal about his affection following the injury than he had been before. She in turn wanted him to know that she would be there to care for him and to keep him occupied. She expressed concerns about him falling into depression when they moved home. In general, most partners were concerned about patients' mental health and aimed to keep their spirits up. This encouragement only went in one direction. Partners encouraged patients and never the other way. For example, at our third interview John spoke about how his wife's encouragement helped him every day. He said:

> Uh…my wife…she encourages me (chuckle)…she says, 'you can do it, you can do it…it just takes you a little longer, but you can do it.' When I get through, she says, 'look at that…that's professional lookin'…you know, it makes you feel good…and she really encourages me.

Patients who received encouragement and reassurance along the way were appreciative of the effort their partners made to help them feel good about themselves and their recovery. Additionally, caregiving partners frequently perceived themselves as unable to show any sad or negative emotions to their partners or other family members. During our first interview Shirley shared a story with me about how she had been holding all her sadness, anger, and hurt inside following her husband's accident. She said that one night it all just came out and she started crying. She initially forgot that family was visiting. She said:

> When I got home, I just broke down and cried. You know I just had to for relief. My niece seen me and said, "Aunt Shirley, why you crying?" And I said, "Oh, Aunt Shirley's got so much on her my mind. That's why I'm crying. But I'll be all right." Because you know then that worries the child and stuff. So I said, "Let me get myself together," because I got my niece here. But, oh, it just came to head, you know, and I just had to release it, but I'm okay.

In this excerpt Shirley's experience indicated that although she is in the middle of a crisis and her husband was in the hospital with a broken back and injured spinal cord, she felt the need to hide her emotions from her five-year-old niece. Our families are the ones who should be allowed to see us at our most vulnerable state, yet the women in this category felt it was an imperative of good and strong caregiving to remain emotionally strong as well.

There were many experiences that patients and partners relayed that were not as overt as Shirley's crying experience in front of her niece. In more cases patients and partners kept their feelings inside without sharing with one another for fear of hurting the other person's feelings. This was frequently happening within couple dyads, yet neither couple approached the other person about their concerns. Derek and Amanda's narratives frequently illustrated the constant negotiations that couples in this category went through in regards to emotion work:

Amanda: I'm like you know what, just do this one thing and it'll be fine. And I want to say, "I do every damn thing around the house, everything, and all I want you to do is this one stinking interview, and you won't even do it?" But then at the same time, that's just a selfish – I mean, if he pushed it, I would probably say that to him, but at the same time, I want him to have some time to be able to just say "you know what, I don't feel like doing it." But at the same time, I also don't want him – that's something he would have done before, but I would have pushed him into doing it. So I don't want to let him get away with shit because that's his nature, I don't want to let him do that just because he's hurt, but at the same time, I don't want to be a brat.

Derek: I think I put on a front for a lot of people, for her sake and just so she won't be so sad. Some days I wake up, and I just don't want to get out of bed. I don't even want to think about it. Or I'll have a dream that I'm walking and wake up and feel like shit again, so stuff like that, just feel depressed some days and don't want to mention it or let on.

In these two excerpts from separate individual interviews, Amanda and Derek were both trying to be respectful of the other person's emotional needs by managing their emotional displays and denying themselves the opportunity to let their own personality show. In the first excerpt, Amanda expressed her frustration that Derek was having a bad day on the day we had our interview scheduled and he did not want to do the interview. She wanted him to meet me and talk just to get out of the house. She perceived his refusal as a potential red flag that he was trying to avoid interaction because of the injury. Her desired emotion was to get mad at him and to yell at him because while his only responsibility for the day was to meet me, she had to do "everything else," and she was mad. But when the time came, she held back. She worked hard at concealing her emotions because she wants Derek to be able to have a day where he can assert his emotions. On the other side of the negotiation was Derek. Derek expressed that he hides his emotions too. He was depressed. He did not want to get out of bed when Amanda got him up, but he hid his emotions so the people around him did not worry. These were complicated

negotiations that couples are faced with on a daily basis, but the couples in the naturalized category did not discuss these negotiations openly with one another.

Being able to discuss emotions openly was a goal of the couples in this category, but caregiving partners frequently hesitated bringing up things they thought might upset their partner. Before the injury, Amanda and Derek had what they referred to as a sarcastic relationship. They "joked about everything." Amanda explained that she had to engage in a level of emotion work when making jokes. She offered the following narrative:

> I don't know if it would be okay for me to make a joke. Is he going to bust out crying? I don't know what he's going to do, so I just kind of draw my boundaries gingerly with that. Derek just got his permanent chair, his personal power chair recently, and I wanted to clean the footrest. I was down, I had knelt down, and I said, "Derek, would you move your foot?" I didn't think about it, I wanted him to move his foot so I could clean the footrest, and he just looked at me and said, "Uh, no." He thought it was hilarious and I just burst into tears.

In this example, Amanda thought that if she made a joke she would cause her husband to cry, yet when she inadvertently said something that Derek turned into a joke, she was the one who ended up falling apart. Their previous relationship dynamics involved a lot of joking and teasing, but Amanda denied that part of herself during the early months following the injury. She was concerned about the boundaries that she needed to maintain for her husband's mental well-being, but started to lose herself along that boundary. When Derek turned her mistake into something that was at the core of his personality, a joke, she perceived this as a reminder of what had changed in their lives.

Balancing Care and Autonomy among Naturalized Couples

Balancing giving and receiving care with autonomy was especially difficult for couples in the naturalized category. Autonomy refers to the freedoms one has to be independent without surveillance. Because patients in this category were more likely to have quadriplegia, caregivers

expressed greater concern about safety and possible health problems. Geraldine, whose husband John was walking and managing his daily life at the time of the interview, was still worried about him getting hurt. At our third interview she explained:

> I had to watch him and uh, help him with you know, watchin' him when he gets steppin' in out the bathtub and goin' up down the steps, uh, he's not drivin' a car yet, stuff like that, no, no…he wants to, but, it's not safe that wouldn't be safe. He's just, he's just that naturalized….and uh, I have to really watch him 24 hours a day because he try anything (laugh)

Her quote highlights her concern about his autonomy, his desire for independence, and her subsequent limitation of that independence. Independence refers to the ability to accomplish tasks on one's own. Keeping watch over everyday activities was common for the partners in this category, especially earlier in the injury trajectory. Additionally, partners in this category had a more difficult time letting go of care and control as time went on.

Having control of care was not always about watching and being there, naturalized caregivers also found themselves responsible for physical care longer than did the caregivers in the other two categories. These couples would follow along the extended care trajectory (see figure 7.1). For example, Amanda said:

> I don't have anybody yet who can do ICs. He doesn't want his friends to do personal care. And I have a hard time in that respect at this – in one way, I want to kind of influence him to learn to be comfortable with it. I mean, just pick one or two people that if I were to be sick or have to go out of town or whatever that he would like to hang out with and would be okay with that. But he's just – he's not there yet. So I don't know what we're gonna do with that…I mean, eventually he'll make a decision I think. But I'm all right not pushing it for now. I'm gonna have to take a break eventually.

Amanda recognized that she would need to take a break from providing care, but she did not have social supports in place to let her have this break. Derek drew a cognitive boundary about what kind of care friends were allowed to offer, and bladder management was not included. Amanda could be more assertive in demanding that her husband recognize the level of work she

has provided, but she did not push in order to maintain peace in the house. Like other caregivers who have provided care for long periods of time, Amanda was experiencing restrictions in her social and leisure activities (Hooyman and Gonyea 1995). Engaging in social activities could help mediate the relationship between stress and well being in their caregiving relationship (Antonucci 1985). However, she allowed her husband to maintain control over the other caregivers he used. She discussed a desire for him to take more responsibility for his care. At our third interview, this was still a point of contention. She said:

> My biggest, biggest gripe is how much responsibility he takes for his personal care. He just won't remember that he hasn't taken his medicine for the day. He won't remember that he needs to drink some water or whatever. He won't remember when his last IC was, that kind of stuff. And I do understand that I can let go of the control, but I'm like what if he goes for 14 hours and doesn't remember that he needs to pee. That scares me. So I keep picking up the slack and it just frustrates me that he won't do it.

Amanda, and other partners in this category, had to constantly negotiate the balance between providing care and giving their partners autonomy over their own care. When partners in this category talked about giving over control, they expressed that their partners either would not take responsibility for their care or they would do things that might cause them harm. In this case, Amanda wanted to give up control, but her fear that her husband will forget to empty his bladder was so consuming that she could not let go of that control.

Caregivers in this category recognized their partner needs to be independent and responsible for their own care, yet in some cases it was just "easier" for them to keep doing the work. Amanda described the process of trying to turn care over to her husband. She says:

> When we were in-patient, we were talking with our therapist about what can Derek do, and I was like, I need him to make decisions about things. It's just totally exhausting to always be thinking about how can we do this so that Derek can do it? How can we modify this task so that Derek can do it? I mean, even just what's the best way to get him up and get him showered and get him dressed so it's the most time efficient. You know, how can I do this and still get the laundry done? So I said that I need Derek to take responsibility for

> things like his therapy schedule and he hasn't done that. I mean, he acknowledged that that could be something he could do and would do, but he hasn't and I've sort of let it fall by the wayside because it pisses me off so much. I'll ask him, like, what do you want to do and what are you going to do, but I haven't created a schedule, per say. I'm really pretty adamant that that's something he needs to do. Just because I feel like, damn it, I'm doing so much shit, you can do one thing. So every couple of days I ask him and say you need to do that, but he'll be too interested in television or whatever else is going on.

Over time, the emotional work and care involved in managing both schedules could become overwhelming for naturalized caregivers. In the beginning they jumped into care with such enthusiasm and it was not until the second or third interview point that they started to realize they needed to put some of the burden back on their spouse. However, because they had been providing so much care for an extended period of time it was hard for either partner to move out of their new routine.

The patients in this category did not take over their own care, yet they felt their caregiving partners restrict their autonomy. Derek, who would not allow his friends to provide personal care or take responsibility for his daily care, told me that he is never left alone. He said: "She doesn't let me [stay home alone]. I tell her all the time that I'll be okay for an hour or two or whatever, but she just doesn't want to. I think she doesn't feel comfortable yet leaving me by myself." During our conversation he did not say that he could do more to take care of his needs; rather at this third interview he was allowing his wife to have control over his daily needs and not speaking up about his own desires.

John's experience mirrored Derek's. During our second interview, John expressed that his wife was constantly watching him when he did things and this became frustrating for him. He said: "I get kinda aggravated cuz I can't do the things I wanta do and sometimes that I know I can do, but she thinks I can't do, you know, and I'll try to do 'em and she'll get kinda aggravated,

cuz she just, she don't want me to hurt myself." Again, in this situation the caregiving partner constantly engaged in surveillance of the patient's activities in order to prevent falls or injury.

The fear of falling was greater for caregiving partners in this category than it was for patients. Not a single patient mentioned they were afraid to fall. This could be because within Creekview, patients were taught how to recover from a fall and in some cases were taught how to fall to prevent most injuries. It could also be that male patients were more willing to take physical risks with their bodies than women. This excerpt from Amanda was a good example of the difference in how patients and partners approached the subject of falling: "It just stresses me out. I'm like, oh my God, what if you fall out of your chair, what's going to happen then? He thinks it's hilarious; he finds it funny. In my head, he finds it funny to stress me out, but that's nothing new, it's just a new set of circumstances. It just grows old." Amanda's perception of this interaction was that her husband's willingness to try to be independent was done to stress her out and make her laugh. She talked about the need for him to take control of his care while simultaneously limiting that opportunity because of fear that he would fall.

In some cases, partners gave their partner more autonomy and trusted them to stay home. Occasionally, accidents would happen. Shirley provided a good example of the first time her husband fell when home alone:

> I was runnin' a little late, I said, Jim, I'll be there, I'm on my way. He said, 'I can do [my bowel program] on my own'…cuz he transfers himself to the stool, you know, I said, 'Jim, don't do, just wait 'til I get there'…I can do it'…when I got in the house, he was on the ground…and it's like 45 minutes he was…I said, 'Jim…why didn't you wait', you know, my heart, you know, cuz on my way, I'm like Lord, let him, you know, try it on his own, cuz I know Jim…he'll do it cuz he can transfer from the sofa to the chair…way he does it makes me nervous, but I mean, he's all the way down, his head…you know, to transfer…but anyway, he does it by himself…but at least he's on the carpet and stuff, too…where, you know, he's in the kitchen…anyway, I said, 'Jim, how long you been on the floor?"…so he was kinda like sittin'…he said, 'well, a while'…oh, Jim…and I'm like, why didn't you wait…so I said, you know,

> so we start laughin'…I said 'why you sittin' there, what are you doin', just whistlin' or what?' (laugh)

While Shirley was running errands she was nervous he would do something that could hurt him. He did, but he did not get hurt. The first time a patient falls at home can create another shift in the trajectory of caregiving. If no injuries are involved, it usually creates an opportunity for the naturalized caregiver to create a break in the level of care they are providing. The worry about accidents limits autonomy, but once they make it past that first incident without harm there is an acceptance that accidents will happen just like they did before injury. Although there might be more assistance required to get off the floor after a fall off a couch or wheelchair, a fall in the house is not the end of the world, as the partners in this category fear it might be.

John, who was quoted earlier about his inability to do things independently because of his wife's fear, experienced some falls while walking, but kept them hidden from his wife. This was a couple that shared every aspect of their lives and before the injury talked about how they did everything together.

> Interviewer: When you fall, what are some reasons that you wouldn't tell her if you fell?
>
> John: I didn't want her to worry about it or stop me from doin' certain things. She get worried about me…when I first started walking with the cane, she said, "Use your walker" and I said, "Well I can't get, I wanta, walk with a cane more and get more balance you know…learn to walk alone." She's just prayin' won't fall and hurt myself…she worries about me.

Since the injury, John has made some movement toward greater independence from his wife and has come to view their time together as part surveillance that did not exist in their relationship before. He believed that if Geraldine knew that he fell while walking she might limit what he has gained in independence. He also viewed this surveillance as an indicator that their relationship

was strong and she was only watching because she was worried about him, which he found endearing.

Self-care and Caregiver Overload

Over time naturalized caregivers recognize the need to care for their own health in order to prevent illness and burnout. This was not a concern for naturalized caregivers at the first interview point, but they mentioned it more frequently at later interviews. Concerns about illness were a little more common among the older women in this category than for the younger women. However, all women mentioned it at one point or another. In the following excerpt Shirley described how she wanted her husband to be as independent and healthy as possible because of concerns about her health:

> Sometimes I think if I get sick, you know. That's why…I know it's so important for Jim to be independent, be able to really take care of himself. But sometimes I think about when I get sick, because I know even before that he really depends on me. But I think about that. And I just – I mean, I know anything could happen with Jim because I told him, I said, "We are gonna be on top of things." I said, "You're gonna stick with your weight lifts." I said, "Jim you can get bed sores that are really bad where you're gonna have to have skin grafts, and they said that's very expensive." I said, "You don't want that. We're gonna go by the book."

This concern about illness and dependence was tied to the heightened surveillance discussed in the previous section. Shirley wanted to make sure everything was “done by the book” in order to prevent further injury for Jim, but also because if he stayed healthy and fit then he would be better able to care for himself if she becomes ill.

Engaging in self-care was about more than making sure that the patient was able to handle some tasks. Partners in this category all got to a point that they were “just tired” and had to say no to engage in physical and emotional work. During our third interview, partners in this category provided narrative after narrative about “needing to rest,” “being tired,” “losing sleep,”

and "wanting to relax." These outcomes are common indicators of caregiver burnout (Ybema et al. 2002). The partners in this category experienced higher levels of caregiving fatigue and burnout than caregivers in the other two categories. Shirley provided a good example in the following quote:

> He wanted to go to Walmart and I just wanted to rest, cuz I mean, like I said, I get up, I have to get up…I don't sleep well…sometimes Jim calls me in the middle of the night to you know, help with his legs…it's not that much but…I don't sleep…I wake up and the AC's blastin' cuz he's hot, I'm freezin', and see he sleeps on the sofa and I'm in the room, so I'm under the covers (laugh)…I think one time, he had to keep callin' me, I was…I was knocked out…that's how tired…I didn't even hear…and usually, I'm a light sleeper, but I was just so exhausted.

The partners in this category have created a catch-22 for themselves. They have put their partners' needs ahead of their own for so long, in part in the name of safety, and they cannot sustain that level of attention. Eventually their bodies will shutdown. In this case, Shirley was unable to hear her partner's call for help. If this had been an emergency, she might have slept through it, which would have cause an even higher level of surveillance on her part. Other partners in this category fell asleep for long periods of time to wake up to their husbands in excruciating pain, which in turn created a sense of guilt.

Partners in this category also neglected self-care when there was clear indication that they needed medical treatment. As Geraldine said at our third interview:

> I was supposed to have some tests done, really, when John first came home on my heart and some things done, and I ain't got there yet, but I've got to get it set up…I gotta get some stuff done, but, so far, so good, I've been, you know, I go see the doctor once a month and I'm holdin' my own, so…my health is not that good…I got high blood pressure and some different problems and a fractured back and, but I just been tryin' to maintain, you know, hang in there, maintain 'til everything gets kinda leveled out…I'm doin' better…I'm doin' ok…I'm kind of a care giver…I take care of everybody else and put myself on the back burner…but I have gotta go get myself…there's some things that's come up that I've got to go get seen about…John keeps wantin' me to go and I keep puttin' it off…but I just, I'm havin' some problems with my legs and all, but…I'll get there…

Geraldine kept pushing her own health off, even when her doctors have indicated she could be in a medical crisis. Her friends and family have not given her the support she needed to take the time to get her health checked. No one offered her support and she was not willing to ask her family for support because she and her sisters were already caring for their frail mother and she felt her friends remained focused on her husband's needs (fieldnotes). Additionally, the doctors she interacted with for her husband's care have not assisted her either.

Although caregiving partners in this category recognized they needed to take care of their bodies and their mental health, few asked for help from family or friends to allow them to do so. For example, Amanda said:

> I think, I mean, I say no, but everybody wants to have girls' night. Everybody wants to have girls' night. Like, "Amanda, you need to come relax and just have girl time." And I do. And I understand that and I will. It's just a matter of lining everything up and all that.

Self-care requires work. For Amanda, getting help would require training friends or family to help with medical needs that might arise and coordinating schedules of people who Derek was comfortable with. In Amanda's case, the time and energy needed to do this was too much for her to take on at this point in time. Furthermore, patients in this category did not provide opportunities for their partners to go out and friends did not do anything other than suggest or ask caregiving partners to come out. However, self-care does not always have to involve leaving the caregiving situation. Having friends to talk to on the phone could be enough for some caregivers. Shirley offered the following example:

> I don't have that many friends. You know I do have a lady that I used to work with, we talk on the phone. We always keep in contact. She's close to me, even though we don't see each other. You know, she works two hours away and I'm here, but we're always on the phone talking, and then emailing each other. Well since then since my aunt moved out here, which is good, I've been talking to her, so that helps a lot, too, because I don't what I would do. You know you need that.

Having the opportunity to vent about caregiving tasks was helpful for partners in this category. Some women were closely affiliated with their church and they found relief weekly church attendance as a way to escape caregiving for a short time.

The construction of caregiving boundaries was a key to mental health survival for the partners in this category. Because these couples spent all their time together (none were working during my study period) they did not have boundaries based on paid work or outside activities and their social roles were tied up in giving and receiving care. One patient, Jim, started playing a wheelchair sport during the study period and, although Shirley had to increase some of her responsibilities to get him back and forth to practice, she found the time he was in practice to be a saving grace for her mental and emotional well-being. She said:

> It gives me some time to be by myself, too, you know, I need that break…cuz when he comes here on Saturday, he [has practice] and has to be here 10:00 and he's done at 1, so that gives me time…I mean, during that time I can wash clothes and stuff, but I don't cuz I know it's crowded.

Just knowing she could wash clothes alone for those three hours helped her manage her caregiving relationship. Other patients did not have a set period of time outside of the home, but partners were still able to create small islands of time or space that was their own. During our second interview Derek and Amanda showered together because it was easier for Amanda to wash Derek while she was also in the shower as well as a way to maintain some intimacy in their relationship. However, at the third interview Amanda indicated that she started showering on her own. She said that time in the shower when she could stand there and just let the hot water hit her in the face and she did not have to "do anything" were sometimes the most treasured five minutes in the day. She still washed Derek in the shower and provided the rest of his personal care, but the option to create her own five-minute oasis has helped her cope with the rest of her day.

Overall, naturalized caregivers initially entered the caregiving relationship without questioning the structural constraints that were pushing them into a full-time caregiving role. Their previous life experiences, such as being poor, female, and unemployed, were structural limitations that influenced their entry into assuming full time care. Additionally, they and their husband's had internalized the cultural myth that women were better caregivers. While it is true that spouses would initially turn to each other for care in a time of need, these couples' existing gender inequality in their home followed through the caregiving career. Women in this category took on a great deal of care and ultimately had a difficult time readjusting to life as the supporter of their spouse and not the full-time caregiver for their spouse.

CONSTRAINED CAREGIVERS

Partners who offered constrained narratives (n=10) felt torn between the amount of care they could provide and the amount of care they wanted to provide. Couples in this category had more equitable relationships before injury and both partners were likely to be employed outside of the home. Care was frequently given because of an expectation of reciprocity and equality, rather than as work. As Robert said: "I always say to her is that it could happen to me, and, you know, we're both 46, 47 years old…in 40 years, she may have to take care of me." Additionally, couples in this category were slightly more likely to have children in the home. Caregivers in this category also neglected their own emotional and physical health to an extent in order to accomplish caregiving tasks in addition to the other commitments they had in their lives. However, constrained couples were more likely to draw clear boundaries of acceptable amounts of care and self-care early in the caregiving relationship. Constrained caregivers had concerns about their adequacy as a caregiver and worried they might do something wrong while providing care. Couples in this category had more autonomy than couples in the naturalized category. This

is in part due to the fact that constrained couples consisted of mostly patients with paraplegia (n=7), which meant that patients in this group experienced higher levels of functional return than patients in the naturalized category. Additionally, couples in this category tended to have shorter marriages (mean=10). Patients and partners in this category were more likely to have more education (all were at least high school graduates and half had a college or professional degree). Patients and partners in this category had more equal incomes. The modal income category for patients and partners was $50,001 - $62,500 and $37,501 - $50,000 respectively. There was one patient and one partner in different dyads who both earned over $100,000. These financial resources meant that couples in this category were able to make renovations to their homes that made caregiving easier and most patients had some form of disability or injury insurance that kept them financially stable for at least a short time after the injury. These same supports were not as readily available for couples in the previous category.

Constrained caregivers received similar formal training at Creekview, but because of other obligations were not as involved in daily care while the patient was still in full time rehabilitation. As such, they were not treated as staff at Creekview and nurses did not rely on them to provide care. Rather, they perceived their role as one involving emotional support and encouragement to help the patient become as independent as possible. As Sarah said:

> I guess they made me feel comfortable as far as knowledge and instruction…they gave me that where I was comfortable taking care of things. He is not your typical situation for there wasn't near as much for me to do, but they made me feel like I needed to make him as independent as possible, so they told me to stand back, but they helped me know what to do when I needed to help.

When examining this narrative in comparison to the narratives of naturalized caregivers, partners in the constrained category were told to stay hands off, whereas naturalized caregivers were reprimanded for not helping often enough while in the hospital. In other cases, nurses and other

staff members did not expect as much from partners in this category as they did from naturalized caregivers. Partners perceived the staff to be understanding and willing to work within the structural limitation that kept partners away from Creekview. Again, Marie provided a good example:

> Interviewer: Are there things you wish Creekview had done differently?
>
> Marie: I don't know if I could, I guess I could say yes. I guess I could say no, but a lot of it was dependent on the fact that of me being able to be here, too, you know, and because I had to work, I wasn't able to, so I think they try to work as much as me in meeting my needs to help take care of Chuck as I could allow them to, based on work and stuff like that…I don't have no real complaints, honestly

Many partners in this category wanted to be more involved in the everyday care, but just could not be at the hospital with their spouse. Marie explained:

> I can't be there and that is hard -- well, I wish I could be up there, you know, all the time, with Chuck, because like in the beginning when he needed to be bathed and things like that, you know, I felt kinda bad because I wasn't there to help out except for on the weekends, but um, I, the one thing that I wish that I could be there more than I'm able to…that would be one of the main things that I would change for myself.

The predisposing characteristics of partners in this category pulled them away from providing care. Partners in this category expressed guilt and sadness over not being able to provide care during their partner's inpatient stay.

Because they had fewer opportunities to provide care in the hospital setting, constrained partners worried about the quality of care they provided once they transitioned home. Constrained partners talked more often about being nervous about their own abilities than they did about their worries about patient safety or being alone. For example, Marie said: "the only thing that bothers me…is just cuz I don't know for sure and you know, if I'm doin' a good enough job meeting his needs in regards to [care]." Marie was concerned that because of her

work or having to care for her teenage child that she was not meeting her husband's daily needs. Diane was also worried about the care she provided, but she was more afraid about hurting Jack. She said: "I'm just nervous, that I'm gonna hurt him, I probably won't, but that's my biggest fear, that I'm gonna do something wrong (laugh), you know…" For both of these women, their biggest fear was centered on their ability to provide good care.

Another key difference between naturalized caregivers and constrained caregivers was the way they approached the care they provided. Naturalized caregivers felt they needed to do whatever had to be done in order to provide care. Constrained caregivers perceived their role as providing assistance rather than doing. As Sarah explained:

> yeah, there, like he has to have help gettin' his brace on, first thing, because I mean that back side, like he'll try to do the front himself, but gettin' that back side on, bringin' his clothes to him, because he can't get up without the brace, so I've gotta go get his clothes, wash his clothes…I get him ready to go take his shower…he's gotten to where once he gets in the chair, I get the chair over there and roll him into the shower, he's pretty much handling that part…but I stay, you know I have to stay with anytime he's transferrin'…toilet transfer, shower transfers, you know, just get whatever he need, basically, I'm kinda his legs right now…that's my biggest thing is just goin' and fetchin' things that he can't get or take him a whole lot longer to get at this point…goin' and gettin' his shaving stuff, going to get his towels, toothbrush…gettin' his pillows, 47 pillows for the bed (laugh)…that's, that's, I mean, for the most part, that's kinda what I'm doin', I mean, that's all I'm really doin', workin' with him every now and then when he'll want to work outside of therapy, you know, givin' that pressure for him to push against…we went to the gym together yesterday, tryin' to make that part of the daily routine…we just go work out together and give him a little more time, cuz he just, he really wants to do more and more

Sarah saw herself as a supporter of Phil's endeavor to become more independent. She helped him get his clothes and put his brace on, but she did not dress him. Naturalized caregivers would dress their partner because it was "easier" or "faster." Constrained caregivers recognized they would not be available to provide care at all times and urged their partners to become as independent as possible.

Patients and partners in this category engaged in more boundary work surrounding issues of care earlier than couples in the naturalized category. Partners in this category spoke up more often if they felt the patient was crossing a boundary related to caregiving. Brandi provided a good example:

> I have to set boundaries for his, our new relationship as far as the way he talks to me, like I was tryin' to do his IC the other day and he spouted out, I mean just, you did it wrong, start over, screamed, you know, and I'm like, ok, God, it's not like you're diseased, it was just touched a second, you know, and he's "jeez" everywhere, blah, blah, blah, anyway and the nurse is standin' there, I'm like, you know, tryin' to get checked off, and I'm like (laugh)…I'm gonna put it in your nose, but that kinda part, the one thing that we have to, they said bickering's good, just that you have to set boundaries, you know, as far as he's not gonna treat you any differently than you did before…it's just that we both have a new, a different way of communicating that way, I guess…

Partners in the constrained category frequently discussed the active negotiation of boundaries during the transition to care, especially early in the care process. When Steve felt his care was not being done correctly he spoke up about his needs. When Brandy felt she was being attacked for providing care, she spoke up. These confrontations were more common among the couples in this category than in the other categories.

Patients in this category also worked harder at creating boundaries around caregiving. While patients in the naturalized category frequently mentioned they thought their partner was being taken advantage of at Creekview, they did not advocate for their partner. However, patients in the constrained category protected their partner's time and advocated for their health earlier in the process. As Chuck explained:

> [Marie's] comin' up on weekends. I think it's important for her to still stay in her daily routine, you know, not to get too caught up in mine, you know, although she wants to know everything about what's goin' on with me, it's just like the medical stuff. We had a conference today with the Dr. and my wife, and myself…well, she didn't come up, but I called her on the phone, put it on speaker and I said, "here you go." There wasn't, I mean, 15 or 20 minutes, for her to travel 2 hours, on a Thursday and take that day off work, to me, I just didn't see that as necessary, I really didn't, so, she agreed and decided to…but

> I think it's important that, you know, we still got a 15 year old that we have to take care of too, but it's important that she still do her like, tonight, I would expect that she goes to yoga. I'll call her, and if she doesn't, I'll be highly upset, because I think she needs it, I really do. She'll come in on Saturday…we thought It would be important just to come up Saturday and leave on Sunday. I got plenty of people that can help me, you know, (chuckle). I got plenty of nurses and doctors and I understand that sometimes, sometimes she doesn't understand, but, she can do more good at home or good for herself, own well-being, you know, cuz that's important to me, you know. I don't want her going crazy…I'm not at home and haven't been home for 2 months, but, I mean, she's been taking care of the bills anyway. She knows how to go to the grocery store, she knows how to take care of the pool, so the weekend's comin' soon, sure…I'd love to see her, love to be with her, yeah, BUT, but that's just, you know, sometimes I can't talk her out of it…

Chuck had genuine concern about his wife's mental and physical health even though it was not a focus of the rehabilitation center. He protected her time by using the phone for a medical conference instead of her taking time from work. Unlike the patients in the naturalized category, patients in this category recognized that nurses and staff were there to provide care and they did not want their partners to give up who they are in order to provide care in the hospital. They wanted to see their partners or spend time with them, but they thought it was more important for life to continue as close to normal rather than allowing care to consume their lives.

Before injury, patients and partners were balancing work and home life and as such they held multiple roles in the community and in their relationship. Following injury, most people in the constrained category continued to wear multiple hats and partners were not relegated to assuming a singular identity as caregiver. Pavalko and Woodbury (2000) found conflicting evidence for the benefits of holding multiple roles (employee and caregiver) among older middle age women as they transitioned in and out of these roles. Because of the complicated intersections of class, gender, age, employment, and recovery, it is difficult to say if the partners in the constrained category benefited or suffered from the multiple roles they maintained. It is

fairly clear, however, that their multifaceted identities from before injury prevent them from being consumed by the caregiving role.

Emotion Work and the Constrained Caregiver

As discussed in the previous section, everyone in this study engaged in some form of emotion work, but the intensity of emotion work varied based on a number of factors. Timing in lives and other family obligations were things that contributed to this variability. For example, Sarah hid her concerns about fertility and health because she wanted Phil to focus on his health, but also because of their newlywed status. She said:

> When we had the medical conference, the big thing that came up that I really just had to swallow and bite down on was the potential fertility problems that come along with [injury]…it's not so much the sex, it's the idea of having kids and knowin' we want family at some point…the fact that that could not be there or that we'd have problems in that area…uh, was kinda scary, you know, cuz this is a big deal, especially newly married, the, that's not what we're thinkin' about today, but in a year or two, we're definitely gonna be thinkin' about it…now, since the accident, if I had a concern that related directly to his situation, I might not approach it with him right now, but later on I would tell him about it, like, once we were past that hurdle, I might share it with him, but for now, if I needed to talk it through with somebody, it wouldn't, it probably wouldn't be him, cuz I don't want to bring him down with, you know, my questions, my concerns about his health, because that's the last thing he needs right now.

The possibility of not having children was a concern for two couples in this study. Although this came up in a medical conference with Sarah and Phil, neither of them discussed it initially because they had been married for only two weeks at the time of his injury. Sarah did not see this as a pressing need because of the timing if the injury and because she was more concerned about keeping his emotions up during the first few months after injury.

Before SCI, patients and partners in the constrained category provided each other with fairly equal support. However, because of the injury, partners in this category found themselves providing more emotional work than they had before the injury. Brandy, for example exclaimed

that her husband's shifting attitude was starting to wear on her by our second interview. She said: "You know, his attitude and state of mind kind of thing, it goes up and down and I'm constantly feeling like I have to be the cheerleader, so, you know, I'm just tired…I'm just tired."

Other partners in this category wanted to be there for their partners emotionally, but again work limited their ability to be physically present. Constrained partners reported using text messaging or telephone calls during their work day to check on their spouses at home. They were concerned their spouse might be lonely, which if not attended to might lead to depression. These partners felt it was their obligation to check on their partner regularly to prevent this. Like Marie says: "I have a break in the day where I can either text him or give him a phone call…I try and do that, cuz, like I said, I don't, I hate that he's here all day by himself. I don't want him to be depressed." Marie gives up her break time at work to check on her husband.

Constrained partners who engaged in emotion work wanted their husbands to be equally willing to hide emotion and pain for peace in the home. For example:

Marie: You know, I try not to let it show, but he, before, he never was one to complain a lot, you know, but sometimes he complains when he's in pain and if he can't do something and or, he'll, and, and I hate to say it, but sometimes it bothers me, you know, because for one, I hate to see him in that state, you know, I wish he didn't have to hurt, and then, another aspect is, you know, I don't know, I'm not in his shoes, so is it just something that is truly hurting, or is it, are you just, I don't know…griping or whatever, …that, that's one thing, I think that…I guess I just, cuz he never used to complain, and now, when he complains, it's kinda, I don't know, hard to take, I guess…

Interviewer: Do you ever say anything to him?

Marie: No, not really…no, not really, you know…I'll just kinda look away and just…ok… (laugh)…I don't know… is it just a little gripe for attention or something and I hope that I fulfill whatever needs he needs, but…I think that's probably my biggest one…you know, like I hate for the kids to hear him, you know, hurt or…cuz that can get depressing to people around you.

The partners in this category acted as cheerleaders, encouraging their husbands to be happy. They had a hard time when their husbands were too vocal about their pain. The partners expressed to me that they do not feel like they can let it be known when they are tired or when they are in pain and because their relationships were built on equality, they want their partner to do the same. In Hochschild's (1989) analysis of the division of labor, she found that couples who espoused the ideology of equality in home and family care engaged in a number of strategies to meet these ideological expectations. Within this study, constrained caregivers engaged in a passive strategy of emotion management in hopes it would change how their spouses expressed negative emotions.

Household Labor, Autonomy, and the Constrained Caregiver

Patients in this category had more freedom than patients in the naturalized category. Partners in this category express letting patients do more independently, in part because they could not be present at all times. Partners had similar concerns that the patient might do something risky or hurt themselves, but they recognized they could not be in control of their partner's actions at all times. Diane explained:

> Right now, yeah, I'm, I'm more on just kinda wantin' to do it for him, which is know, Creekview would probably slap me on the back of the hand for that, cuz, yeah, they do try to teach you to let go, but it is hard, it really is hard. And I hate to think, like ok, I told him he can do it and something happens…how would I feel, you know? If he falls, so what if this happens, you know, so I'm still more with him…but I know, I bet if I weren't here, he'd probably do more things, you know…like if he were home during the day, not working and I was working, I have a feeling he'd probably try to do more…climbing a tree…that's the kind of person he is, you know…he doesn't have a fear of not to try it…but when I'm here, I try keep him grounded, ok, I'll do it (laugh)

Diane was a teacher and at our second interview she was home for school vacation and her husband had returned to work. She speculated that if he was not working he might put himself at risk and while she is home she takes advantage of the ability to "keep him grounded."

Partners in this category also expected their spouses to contribute around the house. Unlike partners in the previous category, constrained categories let things fall into place. They did not take over care and they initially did not push self-sufficiency. Rather, they let the patient take up tasks as they needed. Again, Diane offered a good example:

> I mean he does what he can, but I do notice that sometimes I'm afraid to ask him, are you capable of doin' this, or I just wanted, you know, I don't know if it's something he's capable of doing and but I don't want to push it, you know, cuz I don't want think, well why don't you do this if he's not capable of it (whisper). So I think that's just the biggest thing, is I just don't know if I should say, hey, can you do this for me cuz I don't know where we are as far as should I push it or should I like kinda hold back a little bit about it, you know? Like, making his own breakfast or making his own coffee, should I just say, you know what, why don't you do it, you know (laugh)…I don't know…I haven't gotten there yet as to whether I should say something to him or not, but…like the other day, that toilet, we have a guest bathroom right here, and that toilet's clogged, and he went in and he, you know, got it unclogged for me and stuff like that…otherwise it'd probably still be clogged, cuz I don't know what to do with this, you know (laugh).

In this case, avoiding communication about what can and cannot be done allows Jack to take initiative for unclogging the toilet, something that was his responsibility before the injury. The fact that he has experienced a good amount of functional return also helps with this negotiation because he is able to do the task, but there is still a good deal of ambiguity surrounding his abilities.

While Diane was willing to let the caregiving relationship just work itself out, Cindy was more insistent on asking for help with household tasks. Cindy had to go from part-time work to full-time work in order to help make ends meet while her husband wasn't working and she felt that he needed to do more around the house. She said:

> We go to church and we have this Sunday school class that teaches the Bible, you know, how to keep your relationship good and your marriage good and so he feels like, that if he does the little things, such as, you know, I don't know…whatever you would consider a little thing…you know, to help the marriage, such as maybe puttin' the kids to bed tonight or runnin' me a bath or that kind of stuff, he feels like if he does that kind of stuff, that it's, that he's

> done something grand…but in my eyes, and I've told him this, if he's not pullin' his end of the marriage as a whole, then the little things don't really matter…and so, I mean he doesn't really, he doesn't do anything in the household to keep, you know, things clean or organized or laundry…he'll do somethin' every once in awhile and he's not really supporting our family at this point, so I feel like I'm pullin' way more than my share of the load…so the little things really don't matter to me…but he feels like that he's doin' something grand, so…it's been a challenge.

Reciprocity and exchange were recurrent themes among couples in this category. Cindy was adamant that there be an equal exchange of labor in the house. She was pulling more weight in earning an income for the time being and wanted her husband to pull that weight at home. Cindy and Sam had competing views of what was important to care for one another and for the house. Sam believed he was cooperating and supporting his wife by doing small things and she believed the little things did not matter if the laundry was dirty. When ideologies about housework and care are at odds with one another, tensions arise, which can impact the stability of the marriage (Hochschild 1989). For partners in this study who also worked outside the home, caregiving for their spouse was often a third or fourth shift on top of everything they were already doing.

Achieving autonomy and independence was more complex than just sharing household labor. Patients in this category were frequently left alone or asked to do things quicker than patients in naturalized couples, again because of the partner's work status. Brandy's husband, Steve, had to return to Creekview for the day program without her. She wanted to be with him, but because she was the sole earner in the family she had to push him to be more independent than he might have otherwise been. She said: "He's done really great; I mean he can turn himself. He's very independent. He's stayed in the apartment by himself in Atlanta…he just told me last night, he said,' I'm scared and he said I'm worried…about living by myself up there' and I said,' Well, I have to work, you know.'" Partners in this category felt conflicted about providing safety and security while simultaneously working to provide for the family.

Patients in this category took a more direct approach to regaining autonomy than patients in the naturalized category. Much like Jack took over the clogged toilet, Chuck took his body care back from his wife. He recognized the work she was doing outside of the home in addition to the care she was providing in the home. Chuck explained:

> She was [cleaning up after bowel and bladder care] and uh, I finally, she maybe did about 3 or 4 days of that, and I said, you know what, this is crazy…I gotta find a way…so, I would get myself as far as I could into the doorway of the toilet, where the toilet was at and I could actually reach and, you know, dump my bladder bag and dump the pail, my bowel, the bowel pail from the thing, and I said, listen, you don't have to do this for me anymore, and you shouldn't have had to in the first place…you know, this is, this is something I have to do and I should be doin', so I just took that right off the table.

While patients in the previous category expressed a desire to be independent or not to rely on their wives for care, they did not take an active verbal approach the same way patients in this category did. Phil echoed Chuck's concern in the following excerpt: "I'm, if anything, like I told my counselor yesterday, she tries to do too much for me and I have to get on to her about, you know, let me do things for myself." Phil made this statement during our first interview. Patients in this category were more likely to recognize when their partner was providing "too much" at an early stage in the injury process while patients in the naturalized category did not perceive the level of care as "too much" until they were either entrenched in the caregiving relationship or when looking retrospectively.

Self-Care and Caregiver Concern Among Constrained Caregivers

Both patients and partners in this category were more aware of the need to engage in self-care. Patients were quicker to respond to concerns about their partners' mental and physical health than patients in the naturalized category. For example, at our first interview Gary said his biggest concern about going home was "worrying about her getting just totally worn out,

exhausted." Tim was similarly "paranoid about anything happenin' to" his wife. He knew she was healthy, but he didn't "want her to burn out." Patients in this category were much more worried about caregiver burnout and overload more than the other two groups of patients.

Similarly, partners in this category recognized their limits earlier in the caregiving trajectory than naturalized caregivers. While naturalized caregivers would work and provide care until their bodies forced them to sleep, constrained caregivers tried to find ways to engage in self-care to prevent exhaustion. For example, Marie said:

> Before all this happened, I was going to yoga like twice a week, and I'm tryin' to get back into that routine, but sometimes it's just not feasible, and by the time I get done with all the other runnin' around, I say "forget it" (laugh)…I'm not goin'. But last week I went to a zoomba class on Wednesday, cuz I was, I had, I was doing yoga and then the zoomba class, I'm hopin' to get back into that. But it'll depend on, you know, when Chuck gets the hand controls and until then I'll probably be takin' him to therapy and stuff…or I'll go for a walk with the dog or my neighbor or somethin' like that…

Because constrained caregivers were pulled in so many directions, self-care for these partners was about recognizing the need. One strategy these caregivers used was to create boundaries around what they could realistically accomplish and acknowledge that they do not have to be the ones to get everything done. As Marie continued: "I kinda have to take a step back and tell myself that I'm not gonna be able to get everything done, and so I do what I can do and just leave the rest for when I can get to it." This strategy applied to housework, care, and paid work.

Partners in this category also were more vocal and assertive about doing things to take care of themselves. During my first interview with Diane she expressed a desire to go to a concert and her husband wanted her to stay with him at the hospital. She explained:

> I first told him, I still wanted to go to the Kenny Chesney concert 'cuz I love him, he puts on a great concert. I still wanted to go…at first he didn't want me to go… "I want you to stay with me" and I said, "You know, that's kind of selfish. I am spending all my time with you." We've got 13 and 15 and 16 year old kids that are here by themselves because their parents have to go back to work…you're a 40-year-old man and you want me to stay with you, you

> know? And then I was startin' to ask friends, like am I being selfish to still want to go to this concert?

Diane was able to confront her husband about her need to maintain social ties with friends, which partners in the naturalized category were not as able to do, especially in the months immediately following injury. She had reservations about speaking up and was concerned that her own behavior was selfish, but realized that she needed to continue to care for herself in order to be there for her husband.

Couples in this category also were willing to allow their children to assist with housework to alleviate the burden of care on the partners. Most couples in the naturalized category did not have children who could help with care and they were not likely to ask for assistance. Constrained caregivers were willing to ask for assistance. As Chuck said:

> [our daughter's] vacuuming and doin' that kind of stuff for her Mom, which is great to see, because I, before I hadn't seen that, so that was great to see, you know…that she's chipping in as much as she can. I really like…she…Marie normally went to yoga Mondays, Thursdays and she hasn't been to yoga in awhile, and I think she needs to get back into it…and then she…what did she do the other day…she…on Wednesdays she goes to Zoomba or somethin' like that…yeah, so, I'm like, Ok, go on and do your thing, girl…so, and I think that's a stress-reliever for her, I really do…cuz she works with special ed kids, you know, every day, and, which in itself, can be very stressful…and then to come back, come home to have to cook dinner, to have to, you know, take [our daughter] somewhere or me somewhere, or pick me up from somewhere, you know, so she's constantly going…so, we'll see…

It was important to Chuck that his wife continued to take care of herself to avoid burnout. One strategy that helped with preventing burnout was to ask others for help. In this case it was their teenage daughter, but other people in this category relied on friends or family members to help when necessary.

RESISTANT CAREGIVERS

Only two couples fell into the category of resistant caregiving. Since there were so few couples in this category, I recognize they are outliers from the other couples in this study, yet their reactions to caregiving warrant investigation and this is an avenue for future research. Additionally, there was a lack of information about difficult and negative transitions into caregiving that these spouses described. These two couples were quite different from each other demographically, yet they had similar tensions in their relationships before the injury. One partner was male and one was female. One couple had been married for two years and the other couple had been married for 15 years. One couple included two high school graduates and the other couple had graduated from college. Their incomes correlated with their levels of education. Before injury, both couples had been experiencing other marital strain. One couple was dealing with the resolution of an extramarital affair while the other couple was handling the transition to parenthood and marriage.

Resistant caregivers were not very willing to engage in caregiving until pushed by care workers at Creekview. They were marginalized in the caregiving relationship by staff at Creekview and were more likely to see care as a burden before starting care. While partners in the first two categories were pulled into caregiving by staff members, these two partners were not pushed into taking over caregiving tasks until absolutely necessary. Care recipients in these relationships expressed higher levels of loneliness and engaged in more emotion work to assure their partner was getting their needs met. These couples experienced higher levels of conflict both before and after injury than other couples.

Eddie, one of the male partners in this study, fell into this category. Eddie and Brenda had been married for 15 years and have children, ages 8 and 10 at home. Before Brenda's injury

Eddie worked two jobs and Brenda worked full-time as a paraprofessional at her child's school. Brenda was responsible for all the housework and parenting before the injury. The night of Brenda's accident the two had argued about an extramarital affair Eddie recently ended. Brenda left the house mad and her car hit a tree, resulting in SCI to the T5/6 portion of her spine. While she was in the hospital, Eddie was very resistant to helping with her care and he told me that he had "gone on a bender" for the first few weeks after the injury. He had been sober for three days at the time of our interview and it was the longest he had stayed with his wife since the accident nearly a month earlier. Eddie described his transition into providing care for his wife:

> It's just like, there was a nurse upstairs, she said, "You're gonna have to catheterize your wife before you can leave." I said, "I ain't doing that." She said, "Well, you got to." I said, "Lady, the only thing I got to do is die. That's the only thing I got to do in life." I apologized; I didn't mean to be disrespectful to her, but it's just hard to think of doing that, and the other thing, it's just a lot….I can transfer her now. I can transfer her, and the skin care, and the bathing and all that – I'm good with that. I've just got real issues with bladder care. And bowel care. I know – they said I have to. Will I end up doing it? Yeah. I won't like it, let's put it that way. I'll hire someone at home if I have to...I do things that I've never done before: help her put her make-up on, help with her bath, and getting her clothes on; just being there for her, and making sure she's got what she needs – her cell phone, got pop – she loves pop to drink. She loves the soda pop. I don't know, just trying to be there like a fence post, to sit and drink.

Eddie was very resistant to the idea of providing physical care to his wife. He eventually relented and learned how to provide assistance with ADLs such as transfers and bathing, but was opposed to bladder and bowel care to the point of yelling at a nurse about it. He continued that he wanted to attend to her needs, but based on his narrative, he was not quite sure how to do that. For him, being a "fence post" – a term that conjures the image of hard, stoic, unyielding, and there when you need it – was something he can do.

Nancy, the partner in the other couple that fits into this category, was not as combative or resistant to care. Yet, the idea of care also was greatly overwhelming. Nancy and Sidney were

high school sweethearts who married when she got pregnant following high school graduation. Sidney came from a very religious family. His parents pushed the couple into getting married and having the baby. Nancy and Sidney were struggling financially and emotionally with an infant before the injury. Sidney was apprenticing with a firm to learn skills that might provide them with a more secure future. Nancy did not work and Sidney was opposed to her working outside the home. Sidney was injured when his co-worker, and carpool partner, hit a fallen tree in the roadway on the way to work. In the months following Sidney's injuries, Nancy struggled with depression and substance abuse and was generally overwhelmed at the thought of caring for her child and her husband simultaneously. She explained her transition into caregiving in the following way:

> I know that I feel like out of my mind, sometimes. I just feel really overwhelmed and like I'm just crazy, but I don't really know what Creekview could do to help that. I guess that's just something I kinda need to work on…I don't really know what they could do.

For Nancy, care was just too much to think about. When examining these two transitions in comparison to the naturalized and constrained caregivers, a few things are worth noting. First both partners in these relationships had dealt or were dealing with substance abuse and mental health problems that were serving as obstacles during this time of transition. Additionally, they were not receiving support within Creekview for their needs related to existing relationship problems. When I discussed existing relationship problems with one counselor, he explained their focus is solely on the patient's current mental state. He said: "couples will eventually work out whatever it is they need to work out. This injury provides kind of a band-aid for their problems. I don't want to be responsible for pulling off the band-aid." This approach to relationships in the rehabilitation setting could be setting couples up for failure when they return home to find out the band-aid fell off on the way.

Emotion Work and Stress among Resistant Couples

The couples in resistant category engaged in emotion work less than couples in the two previous categories. Additionally, patients tended to do more reassurance and work to keep their partner happy and comfortable with the injury. Brenda offered the following story about how her husband tried to comfort her:

> [In his mind] if you feel bad, you can go buy yourself something. I think that probably has been one of our big things too, that [before] he would like me to do my nails and do my hair and do my makeup two or three times a day. I'm just not like that. I'm just kind of like, I don't care what people think. I don't – as long as you're not in my bubble, I don't care what you're saying about me, as long as I don't hear it. Since I've been here, he has made sure that I do my nails and put on my makeup. He's actually wanted me to take my picture and send it to him on his phone to make sure I'm putting my makeup on every day. He asked me last night, "Where's my picture?" I'm like, "I already washed it off now." I'm sure today he'll ask me where his picture is because he knows that my spirits are better and my mindset's better when I do something for myself.

A few things are worth highlighting in Brenda's narrative, she described a gendered relationship between her and her husband. His emphasis on material goods and her physicality and femininity before and after her injury were his way of showing affection and care for his wife. Although Brenda did not focus on her own looks, she appeased her husband by engaging in beauty rituals and sending him pictures every day. Brenda perceived Eddie's requests as his care for her and her emotional health. However, she was doing more emotion work in order to reward her husband through this exchange. At times, she engaged in passive strategies, such as telling him she had forgotten to take a picture in order to avoid his requests.

The other couple in this category also had difficulty managing the emotions that come along with injury. Nancy and Sidney were more protective of one another's emotions than Eddie and Brenda, but Nancy had a difficult time watching her husband get dressed in the morning. She said:

> The hardest thing for me to see is him try and dress himself because it's just like, you know, something you learn when you're two. And it's just really – I mean, I get really upset even talking about it because it's really hard for him to do, and it's so hard seeing him struggle just to put pants on. And he's having to like pull himself 20 times just to get something over his ankle, and it's just really difficult to watch. And I try not to let him see that I feel sorry for him or anything because that can kind of hurt his ego for me to feel bad.

In this case, Nancy was protecting her husband from seeing her express sadness or pity for him. One of the main differences in the narrative that Nancy offered and narratives of partners in the naturalized and constrained category was that Nancy did not help him or walk away, but she stayed in the room with him and watched him. Given the previous relationship dynamics of both of these couples along with these last two narratives, it is possible that the women in these relationships were engaging in certain behaviors as a form of self punishment or a manifestation of guilt. In the first excerpt by Brenda, she did not want to entertain her husband's request for a picture. However, she woke every morning and put make-up on with the spoken intention of sending him her picture. Nancy on the other hand stood in the doorway of her husband's room and subjected herself to the uncomfortable visions of watching her husband struggle with dressing. I do not have the data to answer this question of possible guilt or punishment, but with a larger sample there might be more opportunities to explore this question.

Nancy also expressed that the timing of her husband's injury was the most difficult thing to deal with. During our second interview Nancy shared with me that their daughter was just starting to walk and get into things around the house. This point in her child's life caused a lot of stress for Nancy. She said:

> For me it's just taking care of him and a baby at the same time. Trying to learn how to do things for him and – it's just her age. It just happened all – she's getting into toddler stages right at the same time I'm trying to learn about what I need to be doing with him. Like she just started walking and she's into everything and is getting very opinionated and pitching fits so much more. It's just been really hard on those days when he's just acting like kind of a jerk and then she's just crying nonstop and just clinginess and I just want to pull my

> hair out. That's been the biggest things for me. I'm trying not to get too stressed out about things, which I do. It's just on and off. I just get really tired of everything. That's my biggest thing I need to work on is just you get tired of it.

In this situation, Nancy would like her husband to do more emotion work than he is doing. She needs him to not be "a jerk" and to protect her feelings more than he is currently doing. Additionally, because of their financial status, they have not been able to renovate their home. So although Nancy did not assist her husband with most of his care – she was the only one who could get the baby in and out of her room because the door was too small, and he could not access many of the other spaces around the house.

Another distinction of couples in this category was the willingness to allow others to help with care. Unlike the constrained caregivers with children at home, Brenda was adamant that her children would not do more around the house than they did before the injury. She viewed this as being protective of the children's "need to be children," but it might cause difficulty when they transition home. Brenda said that she and her husband will "definitely have to lay some ground rules about doing for momma and not doing for yourself." Perceiving care as a sacrifice and burden from the beginning was something that only these two couples expressed.

SUMMARY

All couples transition through the caregiving career (Aneshensel et al. 1995), but there were significant differences in the ways that each group moved into the career (acquisition), how they negotiated the relationship (enactment), and how they transitioned out or adjust to the caregiving relationship (withdrawal/adjustment). How people move through this career influences relationship trajectories as time passes. Previous research has examined how the caregiving career affects women's health (Pavalko and Woodbury 2000) and the larger implications for long-term care policy (Gaugler and Teaster 2006). Most research about the

caregiving career has examined the gradual entry into caregiving over time. For the couples in this study, their introduction to caregiving was sudden and unexpected. Furthermore, the age and levels of recovery among the participants in this study set them apart from other study populations that primarily include older adults or people transitioning in and out of long-term care settings.

Couples in the naturalized group have internalized the pervasive ideology that caregiving is natural for women (Calasanti and Slevin 2006) and easily transitioned into full-time caregiving, even when their spouse was still receiving treatment in the hospital setting. Both patients and partners in this category believed the partner freely entered into the caregiving role because it was "natural," but when critically examining their narratives with a gendered lens, we see that few women freely chose to be caregivers. Larger social structures of class, gender, and the division of labor all work together to push some women into this role faster and with higher levels of caregiving than others (Calasanti and Slevin 2001).

Couples with more equitable relationships and who espoused a gender ideology that focused on equality had more balance in autonomy and carework for both the caregiver and care recipient. Constrained caregivers wanted to do more for their injured partner than structural limitations allowed. Unlike naturalized caregivers who acquired the caregiving role easily, the partners in this category were unable to easily fulfill a role they too had internalized – that women are natural caregivers. Partners in this category were most likely employed outside the home and their identity was not tied to a singular role, like caregiving. Rather, they held roles in and outside the home, which was partly class dependent (Hochschild 1989). Additionally, these couples had financial resources that allowed them to modify their homes to provide the most independence for patients.

Couples along the resistant trajectory faced the most difficulty with mental health before and after injury. The two couples, Eddie and Brenda, and Nancy and Sidney, were not as emotionally or physically present as other study couples. Both Nancy and Eddie had past experiences with substance abuse and saw the injury as overwhelming to the point that Eddie drank heavily and avoided his wife and Nancy ultimately left her husband following a period of heavy drinking away from the home. Levels of similarity or dissimilarity in psychological distress during illness can impact relationships in a negative way (Kim et al. 2008). There is a dearth of information about problematic caregiving relationships and these two couples are an anomaly within my study. Although these two couples were outliers in my study, I think this was the result of self-selection during the recruitment process and with a larger sample size we could examine these relationships in more detail.

CHAPTER 8

CONCLUSION

Looking back on my personal and academic journey, I am reminded of the importance of the sociological imagination and the importance of linking larger social structures to individual biographies. As Shanahan and Macmillan (2007) reminded us, studying the life course involves examining the events and experiences of individuals within the social contexts they live. It has been over eight years since my partner sustained his injury and much like the narratives of the couples in this study, we have experienced the ups and downs that life with traumatic injury brings on an individual level, but these experiences were shaped by our larger social experiences. But this dissertation – and this research – is greater than my experiences. That turning point in my life brought me down an unexpected path and has created an opportunity to examine the social experiences of couples following injury – not just the medical and rehabilitative experiences.

When I started this project, I hoped to examine how relationships change, positively and negatively, or remain the same following SCI in younger married heterosexual couples and what role the rehabilitation setting played in adjustment for both sides of the couple. In particular, I was interested in the couples' experience of the rehabilitation setting, their adjustment to the caregiving role, changes in informal social networks and shared activities, and changes in gender roles in the relationship.

DISCUSSION OF FINDINGS

The most common theme revealed in the literature about trauma and the marital dyad over the past fifteen years is that of emotional, financial, and marital strain (Gosling and Oddy 1999; Chan 2000; Kreuter 2000; Kowal et al. 2003). Some research addresses the changes in

relationships as a result of caregiving (Degeneffe 2001). Others focus on the changes in sexuality and intimacy following injury (Mills and Turnbull 2004). Additionally, much research about trauma and illness in the family focuses on stress (Boss 1987) and poor health outcomes (Aneshensel et al. 1995) for family caregivers. While much of the research reports on the negative aspects of injury and trauma and although my research indicates that traumatic injury is a difficult transition for most couples, I find there is a complex blend of positive and negative experiences and expectations following injury.

My goal with this research was to examine the sociological aspects of chronic illness and injury and how they are negotiated within the context of rehabilitation setting. I began this research with four main goals: 1) To examine how couples construct their relationship before and following injury; 2) To examine how practitioners shape the experiences of couples following injury; 3) To examine what it means to experience SCI as a non-normative event; and 4) To examine how individual, family, social, community, and rehabilitation centers influence patient and partner experiences of SCI.

The uniqueness of the study design allowed me to examine how this context influenced narratives over time and to compare the progression of narratives, rather than relying on memory interpretation to examine a life altering experience. This dissertation is a piece of a larger research project and, like many qualitative research projects, it yielded a large amount of data and my analysis could have gone in one of many directions. For the purpose of the dissertation, I emphasized the experiences of couples following injury and illustrated the importance of the context of the rehabilitation center plays in this transition. The larger study is unique in the timing of the interviews because there is a paucity of research that includes data collection between one and six months postinjury.

First, I found that patient and partner narratives about their injury experiences were intricately tied to their relationships and interactions with practitioners within the rehabilitation setting. My overarching goal was to remove SCI from the medical model of disability, yet I found that the social experiences during the first six months following injury were so deeply entrenched in the medical institution it was nearly impossible to disentangle one from the other. Using a combination of the life course perspective and cognitive sociology as frameworks and grounded theory analysis of 96 individual interviews and 300 hours of observation, I examined how the staff and policies at Creekview influenced the couples' relationships during their rehabilitation stay and the subsequent transition home. Overall, this study found that the totality of the institution shaped a thought community that emphasizes a return to walking and high levels of physical recovery. This thought community influenced how patients and partners constructed meaning about their past, present, and future relationships. Patients who achieved these goals constructed positive change narratives about the future while those with lower levels of recovery constructed negative change narratives over time. Additionally, because of the dominant medical narrative of *wait and see* regarding physical recovery, participants in this study constructed *fuzzy* narratives about the future that do not indicate positive or negative change. Rather, these narratives indicated uncertainty about what life would look like following injury.

Additionally, I found that the dominant cultural narrative that women are natural caregivers was accepted and reinforced by the practitioners at Creekview as well as the couples in this study. This study advances Aneshensel et al.'s (1995) model of the caregiving career to examine how younger couples move through the caregiving career when the expected outcome is not long-term care placement or death. I found three main types of caregivers, each with their

own path of caregiving – Naturalized, Constrained, and Resistant caregivers. These three groups all moved through the caregiving career, however, the paths they took varied based on individual, family, and structural contexts that shaped the caregiving relationship.

THEORETICAL IMPLICATIONS

This project used cognitive sociology and the life course perspective as guiding theoretical frameworks. These two frameworks are complementary of one another, especially when using the constructionist perspectives of the life course (Holstein and Gubrium 2000). The life course perspectives are helpful for examining how people experience life events within larger social contexts and cognitive sociology is helpful for understanding how people "think" about these processes. At the heart of how people construct and attach meanings are the cognitive processes presented by Zerubavel (1997) – perceiving, attending, classifying, signifying, remembering, and timing – and the thought communities we belong to. Thought communities are groups that we are social members of – such as "churches, professions, political movements, generations, and nations" (Zerubavel 1997:9) – and that impact that way we think. According to Zerubavel, we think on an individual level, but the process of thinking is shaped by the thought communities to which we belong. Being a member of the American thought community means valuing strength and independence (Kimmel 2006), which is at odds with the initial experiences of people following SCI. The thought community at Creekview is situated within the larger American thought community, so when therapists and physicians talk about the goals for recovery, they are reflecting their membership in the larger thought community of Americans. The transition to SCI requires the negotiation of multiple thought communities – American and disabled. Zerubavel (1997) acknowledges that we can belong to various thought communities and can enter and exit thought communities, but he does directly not address the

issue of the negotiation multiple thought communities at one point in time. This study examines how membership in two thought communities influences the kinds of transition narratives that people construct following injury.

Membership in the rehabilitation thought community is one part of the rehabilitation experience. The influence of place and space has been largely underexplored in the larger literature about the modern rehabilitation and injury experience. Most of the research about rehabilitation institutions has grown out of Goffman's work (1961) on the total institution and has focused on the impact the rehabilitation process for those with physical and mental disabilities (Yoshida 1994). These studies have focused on the impact of the institution on self-concept (Yoshida 1994), power relations (Ben-Sira 1981), differing goals of staff and patients (Oliver et al. 1988), and the gendered expectations of rehabilitation (Morris 1991). According to Carpenter (1994:626) there is a "dearth of studies ascertaining how persons with SCI perceive the rehabilitation instruction they received" and this lack of information has resulted in a belief among clinicians that the "traditional rehabilitation program constitutes the most effective and optimal method of service delivery." For lack of other options, this taken-for-granted system of treatment has continued with very little examination of the experiences that people with SCI experience as they negotiate rehabilitation (Hammell 2007).

This study adds to our understanding of the rehabilitation institution as a place that impacts how people experience traumatic injury. The four features of a total institution as conceptualized by Goffman (1961) – singular authority, grouped scheduling, regimented days, and a single goal – were present at Creekview. As discussed in detail in chapter five, these characteristics shaped the interactions of patients and partners and influenced future transitions and trajectories for the couples in this study. The lack of freedom, privacy, and individuality for

patients and their partners during their inpatient days influenced how partners interacted and how they negotiated their own sense of identity through their rehabilitation process. Interactions with health care professionals stripped partners of their partner identity and placed them in a limited caregiving role. Partners were included in therapy and the patients' daily tasks when it was important or valuable to the therapists, but not if it was valuable to the patient.

I believe it is important to note that although the initial trauma of injury is a negative event and patients and partners grieve losses related to paralysis, SCI is not always a negative life event. Rather, it is a complex event that gives rise to a great deal of uncertainty and ambiguity. Given the emphasis Americans place on independence and strength – especially for men (Kimmel 2006) – the expectation many people have is that nothing good can come from injury. However, my findings indicate that there are progressive narratives embedded in the experiences of patients and partners after injury. This turning point, for many, results in a reexamination of relationship dynamics and an opportunity to become reacquainted with one another. For a short time, external pressures cease to weigh on the couple – employers offer a leave of absence and friends care for children – which allows them time to "just be" with one another. The new physical space at Creekview encourages this experience. Although I do not have quantifiable evidence these relationships were stronger as a result of this experience, these couples perceived this change based on the attention they paid to certain aspects of injury while excluding others. For example, couples discussed the lack of time they had together before the injury and said the time at Creekview taught them they needed to spend more one-on-one time together and not take their relationship for granted. They remembered their life before injury as being chaotic and busy and their time together at Creekview as peaceful.

Through this work, I aimed to refine and expand our understanding of the ways in which people construct and interpret meaning, especially in the midst of chaos. Although thinking is frequently viewed as an individual act, Zerubavel (1997) highlights the ways in which the social experiences and interactions create similar ways of thinking among groups of people, or thought communities. Using this as a starting point, I explored how the thought community of the rehabilitation center impacts how people think about relationships and disability. In this case, the thought community of rehabilitation and its focus on recovery, independence, and strength overflowed into the kinds of narratives patients and partners constructed following injury. I found four main types of narratives among the couples in this study – Progressive, Regressive, Stability, and Fuzzy – as well as a ZigZag narrative that is a combination of two or more change narratives. Although we all construct and use change narratives in our everyday lives, this study highlights the ways that narratives are constructed through interactions with others as well as through the six cognitive acts presented by Zerubavel (1997). For example, what people pay attention to or focus on will change the direction of the narrative. If a person is only focusing on physical recovery and none comes, then the narrative will be regressive.

A second theoretical contribution this study makes is the examination of the unexpected and off-time transition to SCI. A goal of this study was to examine transitions and trajectories following SCI, especially how people construct meaning around the transition. The study of transitions and trajectories is central to life course research (Giele and Elder 1998). Most research on life transitions focuses on the expected transitions people experience over the course of their life, such as leaving home, birth of a child, and retirement (LaRossa 1983; Reitzes and Mutran 2004; Settersten and Ray 2010) and most societies have expectations about what is a normative transition (i.e., growing old before having a disability) (Hagestad and Neugarten

1985). One significant contribution of my larger study is to connect this literature with the scholarly conversation of trauma, which focuses primarily on early childhood trauma, social support, caregiving, psychological adjustment, and clinical outcomes (see Dobkin et al. 2006; Furlan, Bracken, and Fehlings 2010). My dissertation also builds on Zerubavel's (2003) work on narrative construction, which examines larger socio-historical narratives of change, and LaRossa and Sinha's (2006) work on how these narratives are constructed during a normative transition to parenthood to examine how couples construct meaning around the transition through interactions with others. Because fewer studies examine non-normative transitions (Donnelly et al. 2001) it is important to understand non-normative transitions across the life course because they help us understand how people grapple with ambiguity and uncertainty during times of change.

Third, transitioning in and out of the caregiving relationship impacts the relationship trajectory. Every couple in this study transitioned through the caregiving career (Aneshensel et al. 1995), but differences exist in the ways that couples move into caregiving, how they negotiate the caregiving relationship, and how they transition out of or adapt to the caregiving relationship. There is a pervasive ideology that caregiving is natural for women (Calasanti and Slevin 2006) and this ideology impacts the caregiving career for couples in this study. Additionally, larger social structures of class, gender, and the division of paid and unpaid labor work together to push some women into caregiving faster or prevent other women from engaging in caregiving (Calasanti and Slevin 2001). For example, the couples with greater levels of income inequality, especially those with partners who were not in the paid labor force, followed closer to the Naturalized caregiving path than couples with more equitable relationships.

The results from this study expand our understandings of transitions and caregiving to include younger marital couples, but they also highlight the fact that people experience

transitions and trajectories differently based on their life course experiences and social locations. By examining what people pay attention to during the transition to injury we can examine how they construct meaning associated with the life course (Holstein and Gubrium 2000). My research indicates that while the individual experiences matter, the rehabilitation setting plays a key role in shaping the experiences following injury. This adds a new dimension to our understanding of narrative construction and the caregiving career not only for couples who are experiencing SCI, but for all people with injury and illness who transition in and out of institutions during their life course. In particular, this study builds on existing research about transitions into and out of caregiving over the life course (Pavalko and Woodbury 2000; Seltzer and Li 2000).

It is important for practitioners and policy makers to know that the heavy emphasis on walking and recovery is shaping people's narratives about their future and can impact mental health outcomes for people who are not able to make a recovery because of the level or severity of their injury. Additionally, because the thought community focuses on the injured partner and not the non-injured partner, they feel left out of the psychological and emotional recovery process and injured partners do not always attend to other people's psychological well-being. These institutions need to do a better job of including both partners in the recovery process and not to rely on the spouse as a caregiving resource alone.

As with much feminist scholarship, Hooyman and Gonyea (1995) remind us that the "personal is political" and the interactions that women have with health systems and public policies shape how they experience this relationship. When considering caregiving relationships, I think it is important for counselors and other health care professionals to be aware of the various kinds of caregiving relationships that exist and how these relationships can alter

relationship trajectories and patient outcomes when people transition home. Counselors encourage partners to take care of their own emotional health and to stand back during the caregiving process, yet they fail to provide them with the tools to make this possible. These findings reinforce the role of the partner in the long-term recovery and adjustment process and rehabilitation professionals need to be more aware and sensitive of the needs of marital couples.

METHODOLOGICAL CONSIDERATIONS

This study raises a number of methodological considerations. The first consideration is related to the sampling, recruitment, and retention of participants in the study. On the surface it might appear that this research is only about one institution and while the place was the same for the duration of the study, the space was not. As highlighted in chapter four, this institution underwent significant renovations during the 18 months I was in the field and during this time the feelings of space and place changed for patients and partners. The experiences of the couples I met toward the end of my study were different than the experiences of the couples I met in the beginning of the study. This finding highlights the importance of space and place on lived experiences following injury.

Additionally, couples who have the opportunity to be treated in a specialty hospital set them apart from other people who are experiencing SCI in locations across the country that do not have access to such specialized care. It is estimated that of the 12,000 estimated new cases of SCI annually, only 15 percent of them receive treatment at a model SCI center (National Spinal Cord Injury Statistical Center 2009) and of those 20 percent are treated at Creekview. This means that the participants in this study were different from other people with SCI because of their exposure to the model system of care, which included clinical research and cutting edge treatments that would not be available in local or regional hospitals.

Furthermore, two of the patients in this study were transferred to Creekview after a short hospitalization elsewhere. They had to fight with their insurance carrier to allow the transfer and, in one case, reported a health violation of feces on the floor in order to initiate the transfer. These two couples had experiences that varied from other participants because of the cognitive lens they brought with them from their former experiences. They were less likely to say negative things about the staff or treatment at Creekview than other patients and partners and provided a generally rosy view of their experiences. This is not to say that other couples complained a lot, but these couples did not offer any negative comments about their care at Creekview while they spoke at length about poor treatment at previous facilities. Additionally, one patient transferred out of Creekview to a military hospital because of his active military status. This was interesting because one other active duty military member was not forced to transfer. In the case of the transfer, this patient was not receiving the same level of physical rehabilitation at the military facility as he was receiving during his stay at Creekview and he reported that his therapies did not focus on walking and gross motor function as they had at Creekview.

Another consideration related to the recruitment of participants has to do with the recruitment and selection of participants. I recruited my participants through five different gatekeepers and I have at least one couple from each person, but a significant majority came from one counselor. This could be for a number of reasons. First, I had a longer standing relationship with this one counselor and he was my main contact at Creekview before I started the research. Second, because of the team setting, some counselors only saw adolescents or older adults, which meant they rarely had people who fit my age criteria. A third counselor worked on a team that primarily saw patients with dual-diagnosis – spinal and brain injury – patients and they were thus excluded as well.

Recruiting and retaining participants with various stories during this life event was also difficult. I can assume that patients and partners who were facing multiple stressors were less likely to agree to participate in the study and those who had difficult transitions home were less likely to return follow-up calls. As such, this sample could be skewed to only include the stories of participants with less stress before and after the transition. For example, I had one couple who had agreed to participate in the study but had not been interviewed, cancel their participation because the wife found out she was pregnant with a second child two weeks after her husband sustained his injury. For her, the thought of being emotionally available to a stranger was too much to take on at that point in time. A broader range of experiences would have led to a greater understanding of how this transition impacts more couples than just the ones who are adjusting well. Additionally, much of what we know about spousal caregiving is from couples who are "successful" at it. Being able to examine the couples who are less successful would expand our understanding of the full caregiving career.

Because of the unpredictability of SCI, it was difficult to achieve variability on a number of demographic characteristics, in particular race and gender. My sample was mostly white and middle class, which mirrored the patient demographic of Creekview during my recruitment. Expanding the number of recruitment sites to include other centers might increase the representation of minorities and lower class individuals. Additionally, future studies should aim to include more male caregivers and greater variation in race among respondents. However, it is difficult to locate partnered women with SCI because only 15 percent of all SCI cases include women (National Spinal Cord Injury Statistical Center 2009). This study contributes to our understanding of how younger caregivers transition into and out of caregiving relationships, but

there are still many unanswered questions about gender and power in the caregiving relationship that could not be addressed with the current sample.

Another important methodological consideration of this study is my position as a researcher and partner to a person with SCI. An ongoing debate in qualitative research is the Insider/Outsider debate and this is especially prevalent in research about race (Zinn 1979; Collins 1990) and gender (Naples 1996; Griffith 1998). This debate is centered on the relationship of the researcher to the people being studied. Being an Insider—someone whose biography is similar to those being researched—shapes the research relationship and therefore produces different knowledge than might be available to an Outsider—someone who does not have a similar biography to the group being studied before entering the group (Griffith 1998).

As a partner to a person with SCI, I was in a unique position of Insider and Outsider to the participants in this study. In many ways this was a great strength. Because of my partnership status I was able to gain entry into an institution that is traditionally very protective of its members. The timing in which I aimed to interview people is a difficult time for people transitioning into life with SCI, but because I had experienced this transition I was welcomed by many couples to take part in their journey. Alternatively, there are a number of facets of life with SCI that I take for granted, such as how the body functions after injury and the need to catheterize or go through the bowel program. This was apparent during discussions with my advisor about my findings. Her questioning of my taken for granted knowledge about SCI made this a stronger piece in the end, but I question what I might have missed during data collection.

Like other scholars, I believe that while my personal biography and knowledge of SCI provided access to Creekview, the interaction of biography and social location influenced my relationship with participants in various and complex ways (Griffith 1998). For example, my

partner and I were not married at the time of his injury and I was not his full-time caregiver following injury. So while I was a partner to a person with SCI, my experiences were different from those of the partners in this study. Additionally, I did not share the same class, education, and gender as many participants. Like Collins (Collins 1990), I do not believe there is a simple dichotomy of Insider or Outsider. Rather, I think there are boundaries that shape our simultaneous Insider and Outsider statuses and our singular piece of biography (race, class, gender, ability, etc.) is not enough to claim Insider status or to exclude others from standing inside and looking out.

During the data collection respondents would frequently ask me questions about my personal experiences with SCI, how my partner recovered, and how our relationship changed following injury. I was open and honest with them about my experiences, but I was careful to share that our experiences might be different than theirs. Some of my respondents placed me in a position of insider and perceived me to be an expert in the field of relationships and injury, but not a medical expert. This was difficult because I knew they were facing such ambiguity during this process and my responses probably did not offer them enough. Additionally, I often wondered if my "successful" relationship influenced people to construct positive narratives in my presence because of a desire to be viewed as also having a positive experience after injury. I did not notice a correlation between my social location and respondents who presented progressive narratives. Rather, I found that respondents who were closer in age to me offered more intimate details about the transition to injury. I think the timing of the injury became a point of reference for me and these couples.

GOALS FOR FUTURE RESEARCH

This dissertation focused on a narrow selection of the data I collected to examine how couples experience the transition to injury. Specifically how the thought community of Creekview influenced the ways patients and partners constructed narratives about change and stability in their lives and the subsequent transition into caregiving. The uniqueness and quantity of data means that there are many more options for future research. For example, in this dissertation I did not explore how people view this event as being on-time or off-time in their life or how social support varies based on the person's social location. I also intend to investigate the sexual and intimate relationships of marital couples following injury. These are just a few examples of areas that could be addressed with the data I have collected.

This study opens a dialogue of how injury and non-normative transitions can impact relationships. Because of the dominant medical narrative of *wait and see* regarding physical recovery, many respondents constructed fuzzy narratives about the future that reflected ambiguity about what life would look like following injury. In these narratives, couples were not sure what they should attend to and there was a feeling of helplessness. More importantly, it expands on a concept introduced, but not developed, by Boss (1980)–*ambiguous gains*. Ambiguous gains reflect the unknown positive opportunities that might come from an event that is perceived as a loss. In this study, marital couples discussed the possibility that injury would strengthen their marriage. However, they were unsure exactly how this would happen or if it would last. This concept needs to be developed further with future studies not only about SCI, but other sudden life transitions.

Another area of research that is worth pursuing is the embodiment of injury. It is clear that the body changes as a result of the physical aspects of SCI. However, it is important to

examine what these changes mean in terms of identity and long term trajectories. I am especially interested in the ways that the dominant cultural narratives of strength and independence and the institutional focus on recovery and walking affect the ways people *think* about their bodies. Furthermore, with a study that has data collection past the six month point, I would examine how sexuality and intimacy are affected by the physical changes resulting from SCI.

CONCLUSION

The experiences of couples following SCI suggest that although the general assumption about life following injury is wrought with negativity, not everyone perceives the transition to injury as a negative life event. When I started this project, I also held the same belief. My life situation was different than most of the couples interviewed for this project and my initial adjustment to life with SCI was a negative life event. Through this process, I realized how much the thought community of Creekview and rehabilitation institutions in general influence the way that patients and partners experience the transition to injury. Additionally, I learned that the transition to injury is complex for patients and partners and this study highlights some of the ways the marital relationship is affected by a non-normative, unexpected transition. Questions still remain about the long term relationship stability among couples and how the social constraints of employment, physical access, and economics might impact trajectories following injury.

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APPENDIX: COUPLE AND DYAD CHARACTERISTICS

Pseudonyms	Children Under the Age of 18	Years Married at Time of Injury
Amanda and Derek Smith	No	12
Anita and Shawn Taylor	Yes	10
Brandi and Steve Moore	Yes	10
Cindy and Sam Jackson	Yes	8
Diane and Jack Green	Yes	12
Eddie and Brenda Brown	Yes	15
Faith and Tim White	No	6
Geraldine and John Black	No	37
Jan and Dean Martin	No	6
Joan and Gary Miller	No	20
Marie and Chuck Wilson	Yes	24
Michelle and Keith Williams	Yes	6
Nancy and Sydney Johnson	Yes	2
Reese and Jesse Thompson	No	4
Regina and Marcus Harris	Yes	12
Robert and Lisa Thomas	Yes	10
Sarah and Phil Anderson	No	0.1
Shirley and Jim Davis	No	10

Patient Characteristics by Interview Number

Age	Education	Income at the Time of Injury	Diagnosis	Race	Gender	Employment Status at First Interview	Employment Status at Second Interview	Employment Status at Third Interview	Cause of Injury
40-44	College graduate	75,001 - 100,000	Incomplete Quadriplegia	White	Male	Full time	Full time	Full time	Fall
30-34	College graduate	37,501-50,000	Complete Quadriplegia	White	Male	Full time	Not employed	Part time	Violence
18-24	High school graduate	12,501-25,000	Complete Paraplegia	White	Male	Full time	Not employed	Part time	Auto Accident
35-39	Some college	37,501-50,000	Incomplete Quadriplegia	White	Male	Full time	Part time	Part time	Abscess
50+	High school graduate	25,001 - 37,500	Incomplete Quadriplegia	White	Male	Not employed	Not employed	Not employed	Virus
40-44	Some college	37,501-50,000	Incomplete Paraplegia	White	Male	Full time	Part time	Part time	Auto Accident
45-49	College graduate	50,001 - 62,500	Complete Quadriplegia	White	Male	Full time	Leave of absence	Full time	Sport
50+	Some college	62,501 - 75,000	Complete Paraplegia	White	Male	Full time	Leave of absence	Full time	Abscess
40-44	College graduate	50,001 - 62,500	Incomplete Paraplegia	White	Male	Full time	Not employed	Not employed	Spinal Stroke
40-44	High school graduate	75,001 - 100,000	Complete Quadriplegia	Black	Male	Full time	Not employed	Not employed	Work
30-34	College graduate	More than 100,000	Incomplete Paraplegia	White	Male	Full time	Full time	Full time	Fall
25-29	High school graduate	50,001 - 62,500	Incomplete Quadriplegia	White	Male	Full time	Leave of absence	Not employed	Work
45-49	College graduate	50,001 - 62,500	Incomplete Paraplegia	White	Female	Full time	Not employed	Not employed	Virus
25-29	High school graduate	75,001 - 100,000	Complete Paraplegia	White	Male	Full time	Part time	Part time	Spinal Stroke
40-44	High school graduate	12,501-25,000	Complete Paraplegia	Black	Male	Full time	Not employed	Not employed	Work
40-44	Some college	25,001 - 37,500	Incomplete Paraplegia	White	Female	Full time	Unknown	Unknown	Auto Accident
40-44	Some college	50,001 - 62,500	Complete Paraplegia	White	Male	Full time	Leave of absence	Unknown	Sport
35-39	College graduate	25,001 - 37,500	Complete Paraplegia	White	Male	Full time	Unknown	Unknown	Auto Accident

Partner Characteristics by Interview Number

Age	Education	Income at the Time of Injury	Race	Gender	Employment Status at First Interview	Employment Status at Second Interview	Employment Status at Third Interview
40-44	Some college	12,501-25,000	White	Female	Part time	Part time	Part time
30-34	High school graduate	25,001 - 37,500	White	Female	Full time	Not employed	Part time
18-24	High school graduate	Less than 12,500	White	Female	Not employed	Not employed	Full time
30-34	College graduate	37,501-50,000	White	Female	Full time	Full time	Full time
50+	Less than high school	Less than 12,500	White	Female	Not employed	Not employed	Not employed
50+	High school graduate	Less than 12,500	African American/Black	Female	Not employed	Not employed	Not employed
50+	College graduate	25,001 - 37,500	White	Female	Not employed	Not employed	Not employed
50+	Some college	12,501-25,000	White	Female	Full time	Part time	Full time
40-44	College graduate	37,501-50,000	White	Female	Full time	Full time	Full time
45-49	Some college	25,001 - 37,500	African American/Black	Female	Full time	Not employed	Part time
25-29	College graduate	25,001 - 37,500	White	Female	Not employed	Full time	Full time
25-29	Post graduate	More than 100,000	White	Female	Full time	Full time	Full time
45-49	Some college	50,001 - 62,500	White	Male	Full time	Leave of absence	Full time
25-29	Some college	Less than 12,500	White	Female	Full time	Full time	Full time
30-34	Less than high school	Less than 12,500	African American/Black	Female	Not employed	Not employed	Part time
40-44	College graduate	37,501-50,000	White	Male	Full time	Unknown	Unknown
40-44	Some college	12,501-25,000	White	Female	Part time	Full time	Unknown
35-39	College graduate	37,501-50,000	White	Female	Full time	Unknown	Unknown