

HOW DOES THE SUDDEN IMPACT OF A DISABILITY WITHIN
THE IMMEDIATE HOUSEHOLD AFFECT SIBLINGS?

by

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Acknowledgments

To my sister, Jackie, Thank you for being my number one fan, my rock and never letting me give up. I know you touch the lives of many disabled people by giving them hope as well, I am so proud of you. To all my other sisters, I am very proud of you all as well, and I love every single one of you more than words can describe. Mom, Dad, and Anna thank you for making me the person I am today. Last, but not least, my beautiful daughters. Jada, you were with me when I started this journey in college, and I know you are now looking after me from above. Mommy loves you. Isabella, thank you for giving me life again, you were my reason to not give up.

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Abstract

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This paper examines the relationship among siblings when they are impacted with a crisis. The crisis in this paper is a spinal cord injury. The theoretical framework for the paper is based on family systems theory. This theory incorporates how the self, roles, and identities are created and impacted by the family in how they interact and communicate with one another. The paper examines how the family interacted and communicated prior to the crisis, during the crisis and how they currently interact and communicate.

Respectively these time periods are labeled as prior to crisis, onset of disability, and adjustment phase. It was found that the relationship amongst the siblings prior to the crisis is identified as “normal” which according to the siblings meant typical brother and or sister relationships. After the crisis, initially the siblings encountered role strains and role conflicts due to role reversals that took place between the spinal cord injured sibling and the younger sibling. After the siblings adjusted to the spinal cord injury, they were able to resume to what they considered a “new normal.”

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Chapter 1

Introduction

The family is a unique, diversified and complicated unit.¹ The family unit can provide wonderful memories that we cherish, as well as provide a sense of comfort and security. Unfortunately, some of the memories created are not cherished ones. Many families, for example, face challenges as children go through different stages of maturity. Some of these challenges are expected, such as disagreements within the household and problems with relationships. More unexpected catalysts may include events such as divorce, drug addiction, life altering accidents and death. These events can reach crisis proportions. According to Patterson (2002), a crisis can be a period of significant imbalance in a family, which can often be seen as a “turning point,” leading to major changes in structure and interaction patterns. The “turning point” will be one of the main focal points in this research, as I focus on what a family endures during a crisis.

Rosenstock and Kutner (1967) observed that a crisis can bring about role changes among family members, in turn altering individual goals of the family. In other words, goals may be altered if for example, a crisis brings about a physical disability. This could lead to one of the family members becoming a full-time caretaker. In reference to role changes, Rosenstock and Kutner (1967, p. 398) said this can be seen as “a negative form of involvement in a social system.” Role changes can lead to a feeling that goals (for example an occupation change due to becoming physically disabled) cannot be achieved,

¹ For the purpose of this study, “the family” is defined in a similar way to Levin and Trost (1992) in that the unit will consist of at least one spousal or single parent with at least two children.

but can also be seen as a process that naturally needs to take place to provide stability. Stability provides a sense of control over a situation. In order to achieve this, various sources of help can be called upon in overcoming a crisis: from professionals such as psychologists, therapists and doctors, as well as family and friends who have experienced similar types of events.

This thesis explores the familial experiences, specifically among siblings, following the sudden onset of a spinal cord injury (SCI). While various in-depth studies have focused on the sudden onset of a life-changing event in families, further research is needed to address how siblings are impacted when one family member has acquired an SCI. A crisis such as an SCI is a good case for sociological study because acquiring an SCI is life changing not only for the person affected with the paralysis but for the surrounding loved ones as well. Greater knowledge about the impacts of an SCI may help future families and household siblings understand the phases the SCI participant (PP) will face with physical and emotional challenges, rather than being blindsided as to what to expect. This brings me to my research question: How does the sudden impact of a disability within the immediate household affect the siblings? This thesis can help shed light on how siblings in the family (not the individual that has undergone the life altering event) are affected by crisis. From a sociological standpoint, this will assist researchers understand how families protect themselves from crisis.

Theoretical Perspective

Family Systems Theory

The framework for the dynamics of the family in this study is based on family systems theory. The family constitutes a system because it is socially recognized and can be defined among individuals. The actual definition of who constitutes family members can vary from individual to individual, but the family as a unit is socially recognized. A system, according to Hewitt (2000, p. 43), is “the words that make up a language constitute a system; each word can be talked about, if not fully defined, by using other words.” According to family systems theory, the family unit is “a natural social system, with its own rules, roles, communication patterns, and power structure, for the most part family experiences are repetitive and are based on patterns of interaction” (Ingoldsby, Smith, & Miller, 2008, p. 168). The authors add, “The family is the greatest source of influence on the child” (p. 169). To gain a better understanding of the process of interaction and communication between the family and how it impacts an individual, we must understand concepts that are interrelated with the individuals and others. This will consist of the self, identity, and roles.

A large part of learning who you are and how you identify yourself stems from your family. Looking to symbolic interaction theory and the work of George Herbert Mead, Michener, DeLamater, and Myers (2004, p. 81) defined the self as “both active (initiates reflexive behavior) and passive (object towards whom reflexive behavior is directed).” Reflexive behavior is defined by Michener et al. (2004) as that which engages in self-perception, self-evaluation, self-communication, self-motivation, and self-control.

Respectively, “the active aspect of the self is labeled the, I, and the object of self-action is labeled the, me” (p. 81). Thus, the *I* is the center of our action impulses, whereas the *me* is our sense of who we are as reflected in the reactions of others. Hewitt discussed what it means for the self to act toward an object. Object, as used by Hewitt (2000), “portrays the ways in which people perceive and act on their environment” (p. 39). An object does not necessarily have to be a person, place or thing, but can be “symbolically designated things, ideas, people, activities and purposes” (Hewitt, 2000, p. 39).

Just as individuals act toward objects, they can also view themselves as objects. According to Hewitt (2000), we can be objects to ourselves because “individuals have a way of anticipating their own conduct, for visualizing themselves as a part of their own environment, and for seeing their own acts in relation to those of their fellows” (p. 50). For example, we can identify ourselves according to roles we play—in this case, siblings. Therefore, “the act of giving oneself the name that others give, makes one an object in ones own world” (Hewitt, 2000, p. 49). To have a self is to have the capacity to engage in reflexive actions—to plan, observe, guide, and respond to our own behavior (Michener et al., 2004). The *me* is constantly engaging with the *I* to determine and reason what course of action must be taken in a given situation. In a situation such as a crisis, the individual must internally evaluate and control how he or she will handle a crisis. For the sibling, this means putting themselves in the shoes of the SCI PP and trying to understand their perspective in order to determine how to act toward them. In reference to Hewitt, the ability to put your self in the shoes of the other person is the *me* part of the self. Hewitt (2000) has stated, “taking the point of view of the other person you are acting towards,

you imagine how they will react based off of your own actions” (p. 53). The ability to understand the other person’s point of view, is not merely reflecting on how they would react, but being aware of how they would feel. Hewitt (2000) added, “We do not merely imagine how another will react to us, but actually feel the sensations and emotions we attribute to them” (p. 53). In such situations, siblings are an important influence on the *me* of the SCI PP, whereas the SCI PP individual is simultaneously an important influence on the *me* of each sibling. That is, the behavior of each is heavily influenced by the actions of the other as they adjust to new roles.

The family also provides a foundation for how we identify ourselves. Identity is defined by Michener (2004) as “the meanings attached to the self by oneself and others” (p. 85). Ihinger-Tallman and Cooney (2005) stated, “Identity influences how one labels oneself and how others label one at any given time or place” (p. 49). Like the self, identity is a social product. In other words, how we identify ourselves changes over time and in certain situations. For example, growing up we learn what is entailed with the statuses (social positions) of sibling and daughter or son, each of which involves the role expectations of being loving, caring, honest and respectful towards other family members. As we get older, we learn more about ourselves and identify ourselves in relation to our current situation or experiences. How we identify ourselves (label) is a relation to how others (family) label or identify us. Because of the ever-changing ways in which we identify ourselves, identity, according to Ihinger-Tallman and Cooney (2005), brings together our past, present and future. So we have established that a major part of how we identify ourselves stems from growing up and what was internalized in relation

to our interaction with our family. Thus, identity is influenced by what we are currently dealing with (such as a disability) as well as how we want to identify ourselves in our future. In my study, I examine how identity is processed in stages (past, present, and future) for both the SCI PP their siblings, as each learns to accept new identities and undertakes new roles.

How we identify ourselves stems both from and reciprocally influences the roles we assume. Michener et al. (2004, p. 529) defined role as, “a set of functions to be performed by a person on behalf of a group of which he or she is a member.” In a sense, roles are behavioral scripts that individuals are expected to enact based on the social position they occupy. Moreover, the role scripts we learn from watching others might be difficult to emulate because of situational constraints or individual personality differences. Thus, individuals are often required to improvise, through a process referred to as role-making. According to John Hewitt (2000), “The image of role making emphasizes the fact that people must often . . . invent new ways of acting in order to create a successful performance” (p. 75).

Individuals fulfill the duties of their roles due to a sense of role obligation. If an individual feels that they are incapable of fulfilling their obligation as, say for example, an older sibling who is responsible for protecting and helping their younger siblings; then the sibling will feel a sense of role strain. According to Goode (1960, p. 483), role strain is “the felt difficulty in fulfilling role obligations. The inability to fulfill roles that you identify yourself with creates role strain due to the conflict of old roles and new ones that are brought on by an unexpected event, such as a SCI.” Role conflicts are defined by

Gullahorn (1956, p. 299) as “a situation in which incompatible demands are placed upon an actor because of his role relationships with two or more groups.”

This study will focus on the role conflict that ensues because of the role reversals that occur between the SCI PP and the sibling, such as when an injured older sibling has to accept a dependent role while a younger sibling must adjust to the helper role. I will also describe the ways in which SCI victims and their siblings struggle to make new roles to guide their everyday interactions.

Thus, identity, self, and roles are all key concepts for a better understanding of how the SCI PP and sibling handle a situation such as a crisis. Another element in adjusting to a SCI is the sense of suddenly being thrust into a lower status within the family. An important element of status is “a social evaluation or ranking assigned to a position in a group, indicating its prestige, importance, or value” (Michener et al., 2004, p. 531). The status of disabled initially produces a sense of stress, anger or confusion. Thus, one is faced with what is referred to as role discontinuity. Michener et al. (2004, p. 76) defined role discontinuity as, “when the values and identities associated with a new role contradict those of earlier roles.” For example, we are taught to be independent productive members of society, when struck with a disability the individual initially may feel dependent on others to do simple tasks. This will lead to a sense of stress. On the other hand, siblings who are the younger in the family may feel stressed when there is role reversal with the older sibling, which ultimately requires them to assume more responsibilities.

Much of the family's influence could be attributed to the fact that the household is built on family rules; once rules have been established within the household they tend to remain. "Human beings have a need to maintain balance in their lives," staying clear from the unknown and from change, the researchers concluded (Ingoldsby et al., 2008, p. 170). When a family faces the unexpected (or unknown), such as a tragic accident, individuals initially do not know how to cope with the incident because it is something most have never even thought about, let alone imagined would affect their families. In this thesis, I will explore how a family deals with sudden changes to family rules brought about by an SCI.

Contribution to the Sociology of Disability

It is clear when doing research on family crises that the spotlight is on the family member directly affected by the tragedy. However, it is unclear what the unaffected family members deal with as they witness their family transition after such a tragic event. When a single family member is disabled by an accident, how are the repetitive patterns of interactions in the family disrupted? This thesis will contribute to sociology by establishing what the siblings deal with emotionally following a family crisis and how the family endures. In most cases when there are obstacles within the household, the process of communication is vital to figure how to approach and/or overcome the obstacle. It is important to consider the normal interaction and communication patterns of the family prior to the crisis and then how they have changed, if at all, after the crisis. Change may not transpire after the accident; in some cases a family may have undergone a tragedy in the past, providing a reference for how to deal with a situation that brings change within

the household. This stems back to the repetitive pattern of interaction and the process of communication that normally ensues within the household (Bavelas, Beavin, & Segal, 1982; Hall 1979; Hooper, 2007; Ihinger-Tallman & Cooney, 2005). Family members may not open up to each other; some may ignore their own pain and resentment.

Research has shown that with the sudden onset of disability, it is difficult for the victim to be socialized into a role that is new. Haber and Smith (1971, p. 89) have discussed how impairment affects an individual by stating, “for the disabled person with irreversible impairment or degenerative disorders, the ‘desire to get well’ is often an inappropriate expectation.” The disability is not only a hard concept to grasp but also will take time to adjust to. Most new roles will take time to adjust to, for example becoming a dad, a widow, or a wife. Although these roles may have an adjustment period, they do not interfere with one’s physical appearance or capabilities in handling day-to-day routines. In addition, these roles are not uncommon; therefore the individual might reach out to others in similar roles for guidance. The role of a new disability, however, may be a more difficult role in which to be socialized. This is because physical abilities are limited, requiring one to adjust and learn how to adapt and accommodate to disabilities, and because relevant role models might not exist among one’s family members or friends. In this thesis, I explore how this ultimately impacts the entire family, as well as the individual, in learning how to deal and identify with their new roles resulting from the disability.

As role theory implies, “If we have information about role expectations for a certain position; we can then predict a significant portion of the behavior of the person

occupying the position” (Michener et al., 2004, p. 8). Unless the family has previously dealt with a similar set of circumstances, I anticipate the members will be confused about how to deal with the SCI. Therefore, all of the members would be impacted. Often roles will change and will create a sense of stress, perhaps because the family members do not identify with, or even understand, the disability. Stress will also be a factor because the person that has acquired the role of a disabled person may not identify with it. From the standpoint of the sibling, a role reversal due to a crisis may be just as hard to identify with; especially if the sibling was the younger sibling. Ihinger-Tallman and Cooney (2005, p. 49) have observed, “Identities influence how one labels oneself and how others label one at any given time and place.” Identities are formed through social interaction with various social networks in which the individual carries out a certain role. So, unless the individual and/or the family have dealt with a disability or have been proactive in the disability community, this new identity can create stress.

Acquiring a disability will affect the individuals’ identities and their roles. Some may misinterpret the meaning of a new role or a new identity. To put this into perspective, it helps to further decipher between identities and roles. Ihinger-Tallman and Cooney (2005, p. 49) have defined identity as “a composite of the behaviors, attitudes and moods the individual adopts and the various meanings they attach to themselves and to others.” On the other hand, roles are, “culturally defined and recognized ways of behaving that are associated with each position” (Ihinger-Tallman & Cooney, 2005, p. 7). The new disability may change not only the victim’s internal identity as she sees herself but also her external identity as how others see her based on her role making behavior. I

argue that the internal and main identity, which has been internalized prior to the injury, will stay intact. However, when an able-bodied person sees an individual with a physical disability, it is obvious to *that* individual that the person is disabled and he or she will identify the person as such (this is especially true when the individuals do not know each other). Having a physical disability is an obvious way to identify the individual but that does not make up *whom* the individual is. The individual is not recreating how they identify themselves as a disabled person, they are merely learning how to use new accommodations. Webster's dictionary (2014) defines the act of accommodating as providing what is needed or desired for convenience. This may create a sense of stress for the individual and those closely involved with the individual. According to Altman, Cooper, and Cunningham (1999), stress can be experienced by all family members because of the various levels of care giving and role changes created by the disability.

Literature has indicated that the siblings are not the primary focus within the family during the onset of the crisis (LeClere & Kowalewski, 1994; Vadasy, Fewell, Meyer, & Schell, 1984; Vincent, 1963). The family, in particular the parents, are generally engulfed with being a helping hand to the disabled individual and/or ensuring their recovery. What is unclear from the literature are the roles played by the siblings. For example, older siblings may take the role of "older siblings", and therefore have more responsibilities and expectations compared to younger siblings.

For many, becoming physically disabled occurs with little experience and it is up to the family to make sense of the crisis in order to move forward (Fortier & Wanlass, 1984). Individuals who have acquired an SCI are more likely to recover physically than

they were in previous years—there are cases on the verge of completely healing the spine with procedures such as stem cell therapy. Even though this is substantial progress for the patient, is it enough progress for those family members who are emotionally affected by the impact of the injury? In order to have a better understanding of the sibling's perspective, we will turn the focus towards what the literature says about the impact of a crisis on the family.

Chapter 2

Review of the Literature

Focusing on the Disabled Child

When a family member becomes disabled with an SCI, the main focus, primarily of the parents, shifts to the one who is disabled (LeClere & Kowalewski 1994; Vadasy et al., 1984). Often this prioritizing deprives other siblings of their share of attention, making them feel that they are not equally prioritized. According to Vincent (1963, p. 109), the emphasis in the family has been on the family member who has the illness, which results in “Ignoring the family unit by excluding the patient’s siblings, the mother’s relationships with her well children, and the impact of the ill child upon the total family.” According to the literature, a blind eye is turned to the sibling’s emotions in the event a family member is critically injured. As previously stated, the literature focus is on the parents and SCI PP but not the roles the siblings take.

According to Vadasy et al. (1984, p. 155), “The handicapped child’s impact upon siblings has been less well recognized as their needs are overlooked by parents and professionals.” In most cases, Longo and Bond (1984) said the efforts of the parents of the disabled are invested in “keeping their children either sick or totally normal” (p. 62). In other words, the parents are consumed either with the disability (making sure the SCI PP is able to do day-to-day routines such as eating, bathing and dressing) or with the SCI PP making a full recovery.

It is necessary to explore the disability from the standpoint of the siblings and the one who has acquired the SCI. This is important because it allows the siblings the

opportunity to provide their perspective of what transpires after a crisis. It gives the siblings a voice, in essence opening the eyes of the other family members that the person directly impacted by the crisis, is not the only one suffering. The sibling has not only taken on a new role that comes with having a physical disability within the household, but has also emotionally suppressed many unexpressed concerns with the unexpected and abrupt changes ensued with a crisis. Curiously, roles between siblings have a tendency to shift and reorganize around the demands of the injured during the crisis and adjustment period following the incident. Researchers have found that feelings are neglected and outlooks on the sibling's future are different from that of their parents (Fortier & Wanlass, 1984; Le Clere & Kowalewski 1994; Patterson 2002; Rosenstock & Kutner, 1967). In other words, parent's views and the sibling's views about the SCI PP and what they are capable of are different. When the dynamics of the family unit transition around a crisis, feelings are handled differently, and what has been learned throughout the years with conflict resolution, support, and communication are put to the test. Interpersonal relationships shift, causing a lack of attention between siblings and the disabled member (Fortier & Wanlass, 1984; Vadasy et al., 1984). McHale and Pweletko (1992, p. 69) concluded, "Differential treatment may take the form of disproportionate amounts of time and attention devoted to the disabled sibling; extra responsibilities, such as household tasks and sibling care giving, assumed by the nondisabled child." There is variation in terms of the process by which people move through the crisis stage: some may never move forward from a crisis. Much of this variation depends on the interaction and communication strategies that families have used in prior years dealing with

disagreements on a much smaller scale. One way or another, the family, according to Ihinger-Tallman and Cooney (2005), will try and resolve the conflict for a sense of balance again.

Structure and Function of the Family

To understand what events take place during a tragedy and the impact on individual family members, it is important to understand the basics of the family: how the family is structured and its function. Each family member shares certain responsibilities. For example, parents are often the disciplinarians and providers, while the siblings often share in daily chores, obey parents and assist with watching over younger siblings.

According to Rosenstock and Kutner (1967):

the structural elements of the family may include the division of labor and performance of tasks, the distribution of authority and the means employed for decision making, the contents and patterns of communication, relationships to other social groups, the manner and range of emotional support, and the perpetuation of personal roles within the family. (p. 400)

Just as each household has its own sets of rules and appropriate roles for each member, the families will also have their own unique way of interacting and communicating with each other. How the family interacts and communicates prior to the crisis will depict how they communicate when the family is actually faced with the crisis. Ultimately, a new identity as a disabled person could be unfamiliar to the family. To understand what it means to be disabled, there would have to be some means of interaction or communication about it. In most cases when there are adversities within the household, the process of communication, is vital to figure how to approach and/or overcome the

adversity and return to “normal.” Much of this is because how you identify yourself is a part of your normal socialization within the family and interaction with your social networks over the years. The disabled individual and those within the family often envision making substantial progress from the initial state the individual is in right after the accident. This is because they want to see the SCI PP well. Another aspect of this is that the family members are going through a state of denial. With reference to the acceptance of a diagnosis, such as a SCI, Fortier and Wanless (1984, p. 19) reported, “Parents may have greater difficulty accepting the reality of the diagnosis, thus lengthening the denial stage.”

According to my study, it was evident that eventually the realization sets in that the disability will forever be a part of the individual’s life (the timing of this varies for each family and it could take months or years). On the other hand, families may have dealt with disability within the family already and have the realistic view that the disability does not mean the disabled individual is substantially different or that the disability is the end to life. Those families who have dealt with a disability may be more familiar with where to turn for social support.

Whether a family is familiar with what it means to have a disability or not, the disabled identity will not be a prominent characteristic; rather the identity will still be associated with who they are according to their roles prior to the onset of a disability. In other words, because the disabled individual was not born with a disability, it was never part of their day-to-day life; therefore they did not have to identify with it. Rather, they identify with the roles they have assumed within the family unit and build character based

off those roles. Also, others did not identify the person as being disabled prior to the accident. Living the role of a person who identifies him- or herself as disabled is not anything he or she thought would ever be. Because one could go most of his or her life *not* having a physical disability or interacting with someone who does, it is hard to grasp the meaning of being disabled, much less identify with it. Once someone acquires a disability, the individual with the disability still identifies themselves with characteristics prior to the injury, and the acceptance of identifying him- or herself as someone with a disability could take time. In addition, a disability is a physical condition; therefore it does not change how you emotionally identify yourself. According to Haber and Smith (1971, p. 88), “the term disability, refers to the pattern of behavior emergent from incapacity-the loss of ability to perform expected role activities because of a chronic physical or mental impairment.” In other words, being physically disabled does not change who you are, it is merely a physical appearance. However, those who did not know the disabled person prior to the injury (especially strangers) out of convenience will identify the person with the disability as the “disabled or handicapped person.”

In the course of completing my study, several important themes emerged. These include: patterns of interaction and effect on communication styles and the social effects of crisis on the other family members before, during, and after accident. Respectively, the time periods after the accident could be referred to as prior to disability, adjustment phase following crisis, and normalization. These various components are important in how families deal with the sudden SCI and how it impacts their future, and these issues will be explored below.

Patterns of Interaction and Effect on Communication Styles

Each relationship within the household consists of different roles with expected types of interaction between the family members. According to Rosenstock and Kutner (1967, p. 400), “Family structure tends to develop relative to a number of areas of family life and in accordance with goals.” The authors added, “Some goals relate to the functions performed by the family for larger society; other goals may be introduced by individuals into the family context or may develop as part of the families shared experiences” (p. 400). With these goals and shared experiences within the family, there has to be a process of both interaction and communication. Interaction and communication go hand in hand; without one, the other does not have its full effect on the outcome of a specific situation. For example, in order to have effective interaction styles there must be an agreement as to how to deal with new communication modes and what the new roles mean to each new member and how to proceed. When a family member has acquired a disability, such as a SCI, it is important that the family discusses what this means to them and how to move forward with attaining goals that have been instilled within the household. Haber and Smith wrote (1971, p. 92), “The disabled person is no longer able to conform to the usual expectations of the interaction systems upon which he is dependent for his/her social and material needs.” Haber and Smith further observed that others must search for new ways to accommodate the needs of the handicapped individual.

In this thesis, I will use symbolic interaction as a theoretical frame to better grasp communication. Michener et al. (2004, p. 14) concluded:

The basic premise of symbolic interaction is that human nature and social order are products of symbolic communication among people; and a person's behavior is constructed through give and take during his or her interaction with others.

First, there is the interaction between parents, which sets the tone for the children.

Depending on how parents interact and communicate with each other, children will learn to interact and communicate with each other and society.

According to Vadasay et al. (1984), problems following an accident are dealt with by the family in terms of the family's pre-accident communication patterns. To help put things in perspective, Schiller and Leik (1963) have discussed what Mead refers to in symbolic interaction as the "universal"; the term universal is used to "indicate the entities that become the frame of reference within which the person views the situation or object" (p. 30). This would involve an open communication process in order to refer to this new universal, "the disability," and discuss what it means for each family member. According to Haber and Smith (1971, p. 94), "the meaning imputed to the condition, not the physical reality, establishes the significance of the limitations." Hence, family members must help each other understand that the disability is not the end of life as they have previously known it. Rather, it is crucial that the family members communicate about the disability in order to lift each other up and to continue on with life, interacting the way things were prior to the disability.

According to Schiller and Leik (1963, p. 31), "Through the process of social interaction a person internalizes these universals (disability) and provides for himself a range of role patterns which will guide any particular action on his part." If the family

communicates well and deals with confrontations in a positive way, the entire family unit likely will help the family deal with the crisis in a positive light. Haber and Smith (1971, p. 94) bring up an outstanding point when they referenced Lemert, stating, “Normalization takes place in informal interaction.” This is something that happens behind closed doors with support of the family.

Interaction between the parents as well as interaction within the household includes interactions with their children. Interacting with children in extracurricular activities often produces favorable outcomes. Some of these activities might include attending small festivals, family picnicking, and leisurely shopping in a mall. When there is interaction such as this, it creates a sense of comfort with each other such that the family will feel a freedom to discuss day-to-day issues or problems that may arise outside of the family unit. For the most part, interaction provides a sense of social support within the family; social support has been viewed as one of the potential keys to well-being, particularly for those experiencing major life transitions (Patterson, 2000).

Patterns of interaction will inevitably change between parents and their children following the accident in which the SCI was acquired, leaving a gap as to how to get back to the normal interaction patterns that were in place prior to the accident. Therefore, the family members are more inclined to achieve what Schiller and Leik have referred to as (1963, p. 34) “interpersonal competence.” Schiller and Leik (1963) said this is

the ability to develop fresh perspectives on prior accepted routines (prior to disability) and to make combinations of ideas and objects and so define new goals, endowing old ones with fresh meaning, and investing means for this realization. (p. 34)

The adjustment phase of dealing with the disability has now begun.

Interaction between siblings has the potential to create strong bonds. Focusing on interaction styles among siblings, Dunn (1983) referred to reciprocity and complementarily interaction. Michener et al. (2004, pp. 254–255) defined the norms of reciprocity by stating that individuals should “help those who have helped them” and that, “small kindnesses that create the conditions for reciprocity are a common feature of family.” There is normally an equal amount of give and take between the individuals.

On the other hand, complementarity interaction is seen more as what Dunn (1983) has called a parent-child relationship, in which siblings—acting much like the parents—will reprimand, praise, and look after each other. This is especially apparent between older brothers/sisters and their younger siblings. Dunn (1983, p. 789) stated, “The interaction styles focus on the processes of interaction and about the consequences of a relationship.” These interaction styles are important because they develop at a young age and shape interaction styles for future purposes. This is because of the dependent state that the SCI PP is in; as the SCI PP makes various accomplishments toward independence, a younger sibling acts more as a supporter rather than a parent. Hence, interpersonal competence is strong between the siblings, because of the support through various obstacles in the course of the crisis.

According to Recchia and Howe (2009, p. 1565), “Siblings spend considerable time together during childhood and thus construct a history of shared interactions that can provide considerable insight into another’s perspective.” Dunn (1983, p. 794) also noted that during childhood, “sibling care giving takes place,” which could explain the ability

for siblings to step in and assist in a caregiving manner when one is disabled. Interactions between siblings after an accident are no longer the same, especially when it comes to physical activities. After the critical time period (which I define as the first year after the crisis) passes, siblings often learn to adapt to the SCI by adjusting to the disability when it comes to interactions enjoyed prior to the crisis. Haber and Smith referred to this as (1971) an “adaptive process”; once the individual has acknowledged the limitations of the disability, they will search for “adaptive mechanisms to normalize his relationships” (p. 92). Haber and Smith (1971, p. 93) also stated, “When the impairment no longer limits the role-relevant activity of the individual, he is expected to resume normal role activities.” In other words, once the shock of the situation has subsided and the individual no longer relies heavily on the family for assistance with day to day routines (such as self-care, independence, driving, and going back at work or school) then the family has gained a confidence in the ability of the disabled individual and can resume to their normal activities prior to the accident. This, of course, will vary according to the severity of the injury.

At this point, it is up to the siblings to encourage each other to improvise and continue with the things once enjoyed together. Drapeau, Simard, Beaudry, and Charbonneau (2000) indicated in their study that the support of brothers and sisters plays a vital role in a child’s adjustment to family transitions. This is because siblings interact with each other on a more intimate level, compared to their parents. For example, siblings will share things with each other that they would not necessarily share with their parents. Siblings are often a stronger support system to the SCI PP in that they are not so adamant

about making sure the SCI PP returns back to the same physical conditions they were in prior to the accident.

Aldous (1977) mentioned a good point when it comes to separating the concepts of interaction and communication by stating that it is redundant to discuss communication alone. Aldous (1977) stated:

The interactions based on the sibling relationship, task management and love, is all concerned with communication, for it is through communication that these behaviors become a part of the interaction currency. (p. 126)

Stryker (1959) also referred to this implication by stating, “That language is a system of shared meanings, and this in turn implies that language is a system of behavior” (p. 113).

The main distinction between communication styles I will be exploring is between open and closed communication styles. “Closed” communication refers to the inability to discuss freely what members of the family are feeling about a particular situation, perhaps because of an authoritarian-led household. Open communication patterns allow the members of the family to freely discuss an issue that has arisen and, as a unit, discover how to address the family member’s concern. According to Ihinger-Tallman and Cooney (2005, p. 12) communication within a system, such as the family, “falls along a continuum from open to closed.” They further added, “very few systems are totally open or closed, but some institutions do fall near the extreme ends.” Closed and open communication patterns can be the same for all members of the family or applied individually to members of the family.

Communication between family members helps to create a family structure that is either healthy or secluded when it comes to dealing with events and the emotions. If there is no communication initially after an accident, feelings may be bottled up, leading to anger, alienation, resentment and/or sorrow. According to Fortier and Wanlass (1984), in their study of family crisis following the diagnosis of a disabled child:

problems were dealt with in terms of the family's pre-accident communication patterns; while the family was organized around the family member that was disabled, and the effect of family members was influenced by the mood of the disabled child. (p. 15)

When a life-altering event occurs, if there is open communication prior to the incident this allows each family member to vent about the crisis and discuss how to move forward. If poor communication skills were evident beforehand, then each family member may become isolated and not know how to move forward. Fortier and Wanlass (1984) said that parents need someone to communicate with who can teach them the new terminology that is related to the disability; siblings too need to be included as “interventions since the handicapped child's condition has an overall impact on family functioning” (pp. 21–22). When there is open communication, family members are more likely to discuss a resolution when there is conflict, hence learning how to move forward when there is a life altering event, enabling a healthy psychological well-being.

Social Effects of Crisis

When there is a crisis, roles within the family are impacted. For example, how the parents handle the onset of a disability within the family may be very different from the

sibling's outlook. According to Longo and Bond (1984), children have less difficulty formulating a new identity than adults do. In this case, the new identity would include realizing there are now limitations due to a disability.

Fortier and Wanlass (1994) found that parents had greater difficulty accepting the reality of the diagnosis. When an incident occurs, such as a crisis, it is common for one or more of the siblings to feel abandoned or left out. Fortier and Wanlass (1994) referred to the lack of attention to other family members as a result of guilt toward the parents' total dedication to the SCI child. The sibling's emotions and coping skills become inadequate. The siblings suddenly feel unsure as to when they can voice how they feel, and instead they insulate how they feel and vent behind closed doors. In my study, this meant crying or feeling upset when no one was looking and being sure to avoid drawing attention to their pain.

These feelings of inadequate coping skills were due to the hurt and overwhelmed feelings the family was already dealing with due to the crisis. The family member who is injured primarily has the most attention during the critical time period after the incident, leaving other family members to feel neglected. According to Longo and Bond (1984, p. 62), "The efforts of the parents invested in the disability could explain the lack of attention to siblings." The parent may fail to relate adequately to the other family members. When this occurs, the family member that is feeling neglected will vent elsewhere, or might hold a grudge towards the parents, due to their feelings of being ignored and ultimately feeling unintentionally neglected. During this crucial time period, LeClare and Kowalewski (1994) mentioned that the siblings of disabled children often

develop emotional and behavioral problems of their own; some of this could be associated with the increased responsibilities due to the changes of the disability.

Chapter 3

Research Design and Methods

This study is qualitative and interview based, and my interest in the topic stems from my personal experience. I was disabled due to a SCI from a car accident when I was 15 years old. At the time of the accident, I was in high school and the oldest of five siblings. Due to my own personal experience, I saw how each of my family members dealt with the accident which led to my permanent SCI. It changed the life path I once envisioned for myself, as well as the view my parents had for my future. It also impacted my younger siblings. Communication was a large part of the process; unfortunately, many feelings in my family were not shared until years after the accident. As the oldest child, the relationship with my siblings changed. After the accident, I no longer felt like the older sister, but the younger sister. My sister, who is three years younger, felt she was responsible for keeping the family intact. Unfortunately, my sister buried her emotions, which ultimately led to a sense of resentment. Meanwhile, my parents were dealing with their own sense of guilt, resentment, and confusion.

Because of the impact that the injury had on my younger siblings, I was curious whether similar experiences were common among other families affected by the same type of life altering event. According to the National Spinal Cord Injury Statistical Center (Feb. 2012), in the United States there are approximately 12,000 new cases of Spinal Cord Injuries each year. Because of the prevalence of spinal cord injuries, the unexpected impact it has on an individual's life, and the lack of research on sibling impacts, I was even more driven to hear what the siblings had to share about their experiences. I decided

that the best way to get this information would be to speak directly with SCI PPs and their siblings.

I am active in the wheelchair community, specifically with those who have Spinal Cord Injuries. I mentor at a rehab center with several other peer mentors who have an SCI. The goal of the program is to mentor patients who have been recently injured with an SCI. Each of the mentors has been injured for several years; therefore they are able to share their experiences of how they have moved forward with their lives, despite the SCI. I also have been involved with adaptive sports; which has also enabled me to meet other SCI individuals.

Recruitment of participants occurred through my connections with the wheelchair and rehab communities. A flyer was provided to the person in charge of the mentoring program at the rehab center. The flyer described the study and requested that individuals interested contact the investigator (contact information was provided on the flyer). The flyer addressed who would be eligible for the study, which included eligibility for the SCI participant and their siblings.

I interviewed two groups of individuals: (a) those who have acquired a SCI (called SCI PP), and (b) at least one sibling from each participant in group #1 (called siblings). I interviewed a total of 14 participants (seven SCI PP, and seven siblings). The SCI PP and sibling were interviewed separately. I conducted six in-person interviews in a variety of locations, including a Rehabilitation Center, the participant's home, and a gym. I asked those individuals who I interviewed to provide a copy of the flyer to someone they knew who might also be eligible for the study. I received a response

within a couple of days from other individuals who were interested. Phone interviews were conducted with the other seven participants, because they lived out of town.

Each of the participants was provided a consent form, explaining their rights with regards to participating in the study. I informed each of the participants that the study would be audio recorded, although their identifying information would be kept confidential.

An interview guide (Appendix A) was used during the interviews. The guide was divided into three different phases: the time period prior to disability, the onset of disability, and the current situation. The reason these guide was broken down into these three phases was to see how the siblings communicated and interacted prior to the crisis and determine if there was a change in how they communicated and interacted during the crisis and after. It was also of interest to see what the relationships endured during the crisis and how this impacted their current situation.

In order to determine the dynamics between the siblings, questions were asked about how the siblings interacted and communicated. The same types of questions were asked about sibling dynamics during the onset of disability, at the time of the injury, and the current time. Of particular interest was how the SCI PP and the sibling were currently impacted; therefore questions were asked that dealt with perceptions towards others with SCI and career path. The SCI PP and sibling were asked similar questions.

Individuals with a variety of forms of SCI (from incomplete to complete paralysis from either the neck or waist down) were included. No one spinal cord injury is the same, they all vary from injury to injury. SCI can occur in the neck (cervical), thoracic and

lumbar areas. The higher the injury the more likely the SCI PP will be reliant on caretakers. Four of the seven SCI PPs had cervical level injuries while the others were thoracic. Injuries can range from incomplete to complete paralysis. This means that the spinal cord has been either completely severed, leading to a permanent paralysis, or incompletely severed, leading to partial paralysis. Of the cervical injuries, two had high-level injuries leading them to have minimal function of their upper extremities.

All participants interviewed were at least 18 years of age. The SCI PPs ranged in age from 20 to 40, while their siblings ranged in age from 18 to 34. All siblings interviewed were younger than the SCI PP. The age difference ranged from two to six years. The accident in which the spinal cord injury happened was over two years ago for every SCI PP. The age at the onset of the disability varied. The number of years since the onset of the disability ranged from six to 22 years.

Table 3-1, below, includes factors that were important when considering what played a role in the impact of the disability. The difference in ages determines the relationship between the siblings and the ranking of their birth order. Number of years since the accident was useful to compare the differences between a SCI PP who was injured six years ago compared to someone who has been injured 10 or more years. The level of paralysis was also important to compare the level of injuries. The higher the level of injury, the more dependent the SCI PP would have to be on the family. For example, a C-5 injury would require more assistance compared to a T-12 injury. The anatomy of the spine starting at the neck contains the cervical spine, the thoracic at mid-spine, and the lumbar spine from the low back to the tail bone. A high level injury would be within the

cervical region (neck), such as a C5 injury, versus a lower injury in the mid-spine, such as T12.

Table 3-1 SCI PP and sibling information

Name	Age at onset of disability	Current age	# of years since accident	Level of paralysis	# of siblings
Aaron Dunn	23	29	6	C-5 C-6	1
April Dunn	21	27	6	Sibling	1
Julie Penn	20	26	6	C-4 C-5 & C-6	2
Janet Penn	14	20	6	Sibling	2
Timothy Rod	18	40	22	C-4 C-5	2
Natasha Rod	12	34	22	Sibling	2
James Hubbard	16	30	13	T-4 T-5	3
Brittney Hubbard	12	27	13	Sibling	3
Mitch Smith	17	27	9	C-6	4
Sandra Smith	15	25	9	Sibling	4
Robert Hooper	14	32	17	T-12 L-1	2
Timothy Hooper	14	32	17	Sibling	2
Analisa Wright	8	20	12	T-3	1
Bobby Wright	6	18	12	Sibling	1

Once an interview was complete, field notes were completed. This was difficult for those individuals who were interviewed over the phone, due to the obvious lack of facial expressions and ability to see how functional the individual was with their injury.

As stated previously, all spinal cord injuries are different. Therefore, one individual could have the same level of injury as the other but may have more of a permanent injury.

I transcribed and coded all of the interviews. Through reading and rereading the interviews, the dominant themes of feelings, communication, and interaction emerged. I then returned to the interviews and coded these for dominant themes. From each of those large themes, subthemes emerged. There was a temporal dimension to subthemes as they fit within one of three time periods: prior to the onset of the disability, the adjustment period, and the current time period. Subthemes were, for the onset of disability: fear of the unknown; for the adjustment phase: siblings serving as a support system and independence leading to a new normal; and for current time period: siblings and SCI PPs were closer to the family and wanted to assist other SCI PPs by pursuing a line of work that would allow them to use what they learned from the disability or get involved in adaptive sports. Other important themes that did not fit within the temporal dimensions were the perceptions of others with disabilities and career choices. Once the codes were developed, I returned to the interviews to recode for each. I also wrote analytic memos to explore the codes more deeply and to synthesize the data from the interviews and codes.

Chapter 4

Findings and Discussion

Prior to Accident

To understand how the sudden onset of a disability within the family impacts siblings, it is important to understand how siblings describe their relationships with each other prior to the disabling event and to appreciate their prior experience with disability. The other part of understanding how the crisis impacted the sibling's current situation was to understand what the disability meant to them during the adjustment phase of the crisis. Prior to the accident, most of the siblings had what they defined as "typical" sibling relationships. For the most part, they had normal arguments and disagreements. Two of the relationships were not as close as the others for various reasons, either the difference in age between the siblings or the over-protective brother/sister combination. When the SCI PP was the older brother, they were always protective of their little sister. They were also adamant about the friends their younger siblings chose or whom they dated. This often led to disagreements between siblings, causing them to lose the closeness they once enjoyed.

The over-protective brother/sister combination was definitely the case with Aaron and April Dunn. In describing his relationship with his younger sister, April, Aaron spoke about his protectiveness toward her: "Ok, we had been close but then she started hanging around my friends, which I didn't like. I was trying to be the big brother and trying to get her to stay away from my friends." This was not necessarily the case when in elementary school. Around this time, the younger siblings were intrigued with what their older

siblings were doing, so they tagged along with their older sibling, not because they didn't have their own friends, but because they wanted to be around the older crowd. Due to Aaron being the older brother, he felt it was his role obligation to protect his younger sibling.

When there was a large difference in age, the older siblings tended to assume the role of a parent figure. Again, this was an unspoken role obligation. This type of relationship is referred to as a complementary role. Julie Penn recalls, "Since I am the oldest girl, I was the independent one. I had to help cook, do the dishes, take care of my sister, do her hair, make sure her clothes were together, make sure she got a bath." The younger siblings had a different take on the role their older sibling played. One word to describe it was "bossy." Each sibling perceived with each other from the standpoint of the roles that were taken. The older siblings tended to perceive the younger sibling as lacking responsibility. They understand that they have an obligation, communicated by the parents, to assist with household responsibilities and look after their younger siblings. The younger sibling on the other hand, identified the older sibling as an authority type figure, much as a parent. This was because the older sibling had the right to tell the younger siblings what to do. Janet Penn, Julie's younger sibling, explained, "I remember I didn't really like her that much at times because she was mean and tried to boss me around."

Some of the older siblings took pride in their roles as the older sibling because of the responsibilities that came with it. Timothy Rod described his role as a big brother:

I was a little overbearing. I was kind of, in a way, a third parent. I'll admit I was very-I'm in charge. I'll tell you what to do, especially if mom and dad weren't there. I had no problem throwing my weight around, but at the same time I enjoyed hanging out with them.

When the older sibling spent time with the younger siblings, they got along well. Playing sports together is an example of quality time between the siblings. This also instills a sense of identity based on time spent with family.

Coincidentally, for all the sibling pairs I interviewed, the SCI PPs were the older sibling and the non-SCI sibling was younger. Therefore, I am only able to speak about the roles of the SCI PP as older sibling and the non-SCI sibling from the perspective of the younger sibling.

Sports were a recurring theme in sibling relationships. All my participants, with the exception of one family, were active in sports. In my study, because all of the SCI PP were active in sports and their younger siblings were involved by participating or supporting, this was a driving factor in assisting the SCI PP after the accident with the adaptive process. Sports brought a unity between them. Sports provide an identity of someone who is active and healthy and a social network with whom one can identify. It brought unity to them because they spent a lot of time together after school playing sports. For example, Tim Hooper and his brother Robert Hooper, "played a lot of basketball, literally every single day." It brought them closer together because the older sibling would take the time to teach the younger siblings how to play or perfect their game, such as in the case with the Hoopers. When reflecting on the type of impact sports had on Timothy Rods growing up, he recalls, "I mean my whole life really revolved

around sports. I can remember teaching my brother and teaching my sister to play sports, which was a huge thing for us.” The more the siblings were involved with sports, the more time they spent supporting each other at the games. Even if you were the youngest sibling you were sure to be at every game. This was the case with Timothy Rod’s sister, Natasha Rod: “Because I was the youngest, I kind of went around to where my brothers were and they were in sports always, so I was at a game everyday.” It was a family event. For the Hooper and Rod family, sports were a norm in their household.

If the siblings were involved with sports, the injury impacted whether they would be able to continue to play. Many did not realize at the time of injury that this was a possibility. Once they figured out that it was still a possibility to enjoy their hobbies, they ended up on some type of sports team or became active in working out. To be able to continue to play sports or work out appeared to be a great healing mechanism in the rehabilitative process. It lessened the feeling of role discontinuity; rather it led the SCI PP towards independence. It also provided the opportunity to meet other SCI individuals who had been injured much longer than they had. Mitch Smith explained it, stating, “I never even knew this world existed, but it definitely does. Being involved with wheelchair rugby and traveling all over the US playing-I mean I have friends in every state now.” The SCI PP is able to still identify her- or himself with those qualities enjoyed with being an athlete. “We definitely live life differently, but we still do anything and everything that we want and I think being involved in the sports helped teach different tricks and definitely made life easier and better for us.” The ability to continue to do what you enjoyed doing prior to the accident, such as sports, provides an uplifting

and educating experience for many of the SCI PPs. This proves that when a crisis occurs, it is up to the individual not only to recognize that life is different in a wheelchair but also to evaluate the situation and figure out how to continue on with life, to the extent possible, as it was prior to the accident. The individuals have a choice to overcome and adapt or give in to the stereotypes of someone with a disability. Before discussing the SCI, let's get a brief understanding about the injury itself.

With a severe injury such as a SCI, many unforeseen responsibilities are associated with caregiving. At this point, there is an obvious role reversal between the SCI PP, who is the older sibling, and the younger sibling. This is when role discontinuity sets in with the SCI PP and the sibling, creating a sense of role strain for the SCI PP and role conflicts with the sibling. This does not mean that the SCI PP is not independent, merely that they rely on someone to help him or her get ready for the day and end the day. Role conflict occurred in Julie Penn's description of a typical day for her mother who had multiple roles (caretaker, mom, and employee); she stated the following:

Around 5 in the morning, she gets up and dresses me, this is on the weekdays, she dresses me and then gets ready for work. Then she goes to work and teaches from 8 something to almost 4, and then she comes home, cooks and rest for a little while. Then around 9:30-10 we do my nightly thing, she gives me a bath. Then she goes to bed around 11 or so, her days are long.

Initially after the disability, it is a family affair for everyone to get involved with helping the SCI PP. It helps both the SCI PP and sibling if they have someone other than the family member to be the primary caretaker, this way the SCI PP feels independent from the family and the family members can focus attention on their other siblings as well.

Role conflict creates a sense of stress and guilt for those involved—guilt for the SCI PP because he/she understands the conflicts and strains the caretaker feels. Plus, at the early stage of the disability, SCI PPs feel role discontinuity as they are unable to fulfill their role obligations as older sibling. This is especially crucial for the youngest siblings.

Unless there is clear communication among the family members as to what is expected from them, how the injury has impacted their lives, and what the ultimate goal is for the SCI PP, then some harbored negative feelings are brought on by role strain, experienced by others, and role discontinuity, experienced by the SCI PP.

To understand the added responsibilities held by the sibling due to role reversals, it helps to look at what types of responsibilities the SCI PP had over the younger siblings prior to the crisis. This will give us a background as to what types of transitions took place at the time of the crisis. Julie Penn was a middle child whose mom worked a lot. Role reversal is addressed when Julie recalled how, prior to the accident, “We [she and her brother] had to be the adults when mom was away,” and she added, “we had to take care of my sister and take care of the house.” After the accident, Julie recalled that she felt as her little sister had to step up to the plate to assist her with her daily living by stating, “I’m the big sister but she kind of had to take the big sister role in a way, she helps out a lot and seems ok with it.” This is a fine example of role reversals, whereby the younger sibling is now caring for the older sibling in the same manner that the older sibling did prior to the accident, in complementary fashion. The self is evaluating what action needs to be taken by the sibling. As siblings, they feel obligated to reciprocate how the older siblings care for them. As Timothy pointed out, he “prided himself” on being

the big brother, and when the reversal takes place the older sibling feels like this pride is jeopardized because of the limitations of the disability. All the older sibling wants is to continue to be looked up to and respected as the older sibling. Referring to role discontinuity, this is because the values and identities associated with a new role contradict those of earlier roles. Although roles reversed with respect to complementary interactions, reciprocity was unknowingly taking place. I say unknowingly because it appeared to be more of an awareness from the SCI PP when thinking about the extra responsibilities their younger siblings had to take, while the younger siblings were reciprocating while interacting in a complementary way. This is an example of how the self-engages in self-perception and self-evaluation. The sibling acts according to what they observe by stepping in as the “older sibling.”

When discussing role reversals, Julie added, “At first I was a little worried she [her younger sister, Janet] was going to be embarrassed by me or whatever, but she doesn’t seem to be. She seems cool with it. It made me proud.” This remark insinuates that Julie worries about how her younger sister views her, and when she realized that her younger sister still wants to involve her older sister with what is going on in her personal life, it makes her proud. It reinforces how Julie identifies herself as a caring, loving and concerned sibling. Julie recalled how she felt when Janet asked her to go somewhere, saying, “The fact she still wanted me to be with her, cause she’s kind of shy, so if she wanted me to go somewhere with her, she was like, can you do it with me. She still wanted my support basically.” Julie liked the way this made her feel because she felt like she was playing the role of older sibling. So I think that’s what made me feel respected,

like I was still the big sister.” Julie’s sister, Janet, recalls how she felt seeing her sister deal with reactions from family members, saying:

Some family members would be all sad or try and do a lot of things for her and I could see that upset her, so I would kind of be like a big sister towards her, make jokes about something, try and cheer her up. I would still try and treat her like the big sister, so that kind of helped her out, made her feel like somebody, made her feel the same.

This is a good example of reflexive behavior and how the *me* is able to put itself in the other person’s shoes in order to act in a way that uplifts the SCI PP’s feelings. As Hewitt stated (2000), the *me* is not only the ability to react in a physical sense, but also emotionally connected. Julie acted out according to what she perceived when her sister was looked down on, and acted in a way that would make her feel like she was still the same person. It is evident based on these examples that there is an apparent role reversal, not an intentional act but an act of love. The siblings were aware of how emotionally hurt the SCI PP was and sensitive toward their situation, ultimately wanting the SCI PPs to realize they were still the same person in their siblings’ eyes as they were prior to the accident.

Natasha Rod described how she felt when her brother Timothy Rod came home, saying:

I went from being not the little sister so much, but feeding him, cleaning him when he gets crumbs on him and I have to wipe off the crumbs, that whole thing was like, suddenly he was like one of my baby dolls I was taking care of. It was fun for a while, then it’s not so fun anymore cause it’s like you were supposed to be taking care of me, not me doing this, and then you would get mad at yourself, like, really, you’re mad at him because of this? But I was 12. I couldn’t help it. You’re a little bit selfish.

This is a perfect example of how roles reversal between siblings creates a role discontinuity leading to role strain. Naturally, this situation was not planned, but it does make the sibling reflect on how things were before versus now.

There were some notable differences between the families that have a SCI PP who had only been injured for six years and those for whom the accident occurred more than six years ago. Even though both groups of SCI PPs were independent, the siblings in the more recently injured group still had unanswered questions about the disability. For example, April Dunn, a sibling, questioned if she would ever be able to have nieces or nephews. Janet Penn, another sibling, questioned when she would be able to live an independent life from feeling obligated to help out as a primary caregiver for her SCI sibling.

On the other hand, when the injury occurred six plus years ago, the families were well adjusted. They have lived life with the injury for many years and were adjusted to a “new normal.” This new normal means that they are living life as they would have prior to the accident, except that they are now living their day-to-day lives in a wheelchair. For siblings, the new normal meant they were not closed minded when it came to the ability of an SCI, did not take life for granted, and had a stronger bond and appreciation for their sibling. A new normal for the siblings also meant that they wanted to help others who were disabled. The role discontinuity and role strain has subsided since they were living according to how they identified themselves prior to the accident.

At this point, the parents no longer felt they had to closely monitor the SCI PP. The siblings also had continued on with their lives. The SCI PP and sibling were very knowledgeable as to what to expect with the injury and were fully prepared to open up to helping others that had recently gone through the same thing.

The SCI PPs are productive, successful members of society. Five of the seven SCI PPs graduated from college. They worked and had hobbies. Work consisted of sedentary jobs in fields, such as real estate, technology, accounting, and education. As far as hobbies, three of the SCI PPs mentored at the same rehabilitation center they attended, and a couple played adaptive sports, such as basketball. One of the SCI PPs loved attending concerts; she did not let crowds stop her or deter her from seeing her favorite artists. One of the SCI PPs sponsored a nonprofit neurological gym designed for individuals with disabilities. He was passionate about working out and seeing others work out as well. Many of the siblings had families of their own. At the time of the interviews, only one of the SCI PPs had a child.

Onset of Disability: Fear of the Unknown

The accidents experienced by my interviewees varied from car accidents, motor cross, swimming, high school football, and a fall from a tree. When the crisis happened, each SCI PP initially knew something was severely wrong when they could not move their lower extremities. This was followed by fear—fear of the unknown. No one was prepared for what it meant to be disabled or how to handle the physical disability itself. They did not know how to identify with it. Prior to the accident, most of the people I interviewed had never experienced any contact with someone who had a physical

disability. The few who recalled having had some sort of contact reported similarly indifferent reactions when they encountered a wheelchair-bound person.

The appearance of the disability did not mean anything to the interviewees. This could be because they were able-bodied, young, and immature. Natasha remembered, “There was a kid in our school who was confined to a wheelchair, but it really didn’t faze me back then.” What if the disabled person was someone within the extended family? In this situation, the indifferent reaction still applies. If you are young at the time that you encounter someone with the disability, it still does not mean much. This is the case with Brittney Hubbard. She stated that she and her family had been around family members who had physical disabilities: “I had a cousin that had cerebral palsy. As a kid it didn’t mean anything to me, but as an adult it’s a whole new eye opening experience.” Even then, unless you live with the handicapped person, the able-bodied cannot appreciate how much work it takes just to get through the day, and to perform tasks that are mundane. You also do not realize how important to the disabled it is to have certain modifications available. The exception to this was the Hubbard family, who had been around disabilities prior to the SCI injury.

There is a common negative portrayal of people with disabilities in our society, such as on TV. The disabled are often seen as nonproductive members of society. Julie Penn recalled the uncertainty of what it meant to be disabled by stating, “Usually on TV or the movies you see someone that is paralyzed and they are laying in the bed all the time, so I didn’t know.” Others shared that reaction. Aaron Dunn said, “When you have a spinal cord injury so many negative thoughts start running your mind, you don’t know

what's going to happen. I mean you don't know the outcome." Aaron was injured while riding his dirt bike. He added that, "You're scared, and you don't know how severe the situation is yet." Timothy Rod knew something was wrong and immediately thought the worse. He said, "I knew right away everything I worked for was gone. All I ever wanted to be was a high school coach or a college coach. Everything I worked for, done." This might be a realistic view, but the injury is definitely not the end to being a productive member of society. For Timothy this was an automatic assumption. He had received his share of broken bones and other sports-related injuries when he was a player, but this time the damage was permanent.

Like so many people, several of the SCI PPs felt invincible, that a permanent injury could never happen to them. James Hubbard said, "It just never occurred to me that anything bad was going to happen to me, until I woke up paralyzed. It had never crossed my mind that I was going to be in a wheelchair." Mitch Smith also said, "I was really quite surprised that this world even existed. I mean we weren't sheltered. I thought everyone that broke their neck died." It was a revelation to him and to the other SCI PPs when they realized that they were surviving but that their whole world had changed almost in the blink of an eye.

For some, once the SCI PP is told about the permanence of the disability, the magnitude of the impact on the future may not sink in immediately. Robert Hooper, who was injured when he fell out of a tree as a child, stated:

I didn't really understand at the time that it was going to be a life-long issue. It was kind of a progression of understanding. At one point I

couldn't feel anything below my legs, and then feeling began to come back.

It usually is not until the SCI PP begins the rehabilitation process that the patient begins to understand that total recovery probably is not possible. Julie Penn, who was injured while she was driving with her family, stated, "Once I got to rehab, I saw all those around me and recognized that I was in the same position. That's when it finally hit me. I was scared and I cried. It was more of a fear of the unknown." Mitch Smith, who was injured when he dove into a pool, described the same feeling, "I went to a rehab institute to start my rehabilitation and that's when it really hit me. I had a lot of hard time dealing with it all and trying to accept what had happened to me. I mean, it was very difficult." Until the SCI PP begins the rehabilitation process, they are unaware of what lies ahead for them.

Some of the other feelings that crossed the SCI PPs' minds once they realized that their current state had only limited possibility for improvement were that they started wondering how they would be viewed by their siblings. Timothy Rod, who had always relished being the big brother said, "I prided myself on being the big brother. It was like, 'You don't have to worry about anything. I got this.' It terrified me that my brother and sister weren't going to look at me that way anymore."

The reality of the disability is not an easy concept for many of the family members, especially the parents. While the patient is in rehab and the physical therapists are teaching the SCI PP how to live with the paralysis, the patient may feel like all the focus should be on controlling emotion and learning physical skills. This was the case for James Hubbard, who said, "I pushed everyone away, and I refused visitation. I went

weeks without a single visitor because I had to get up and get moving and get my life back on track.” Since all SCI PPs want to become as independent as possible, it sometimes helps if the patient is alone during this process. James is the only one who refused to allow family to visit, but other SCI PPs did recall how overwhelmed their parents were with the disability and ensuring they walked out of rehab. Mitch Smith recalls just wanting to be left alone at times as well, saying, “Everyone wanted to help, which I understand, you know, but they always wanted to help. Sometimes I didn’t always want them to help.” This of course varies from SCI PP to SCI PP. It is hard on the other family members to be shut out when this happens, however.

Siblings are just as confused as the SCI PP, maybe even more so. Not only do they not know what it means to be disabled, but also they do not actually feel what their injured sibling feels physically. Natasha Rod, whose brother Timothy was injured while playing high school football, stated:

The injury was explained to me, but I still didn’t really understand, oh no this is permanent. He’s not just going to get up and walk away later and take me to the movies. So then I pictured him on crutches. It didn’t really sink in until he got his wheelchair. I’m thinking, “OMG.”

Until siblings have actually taken on the extra responsibility of helping the SCI PP, they do not realize how seriously the disability has impacted the family. Natasha Rod recalled when her brother came home:

He couldn’t lift a fork to feed himself or to hold a cup to drink anything. I went from him taking care of me, to me suddenly caring for him like a baby. That was like a whole new reality. I was just 12, so that part was awkward and confusing, no matter how much as my parents tried to talk to me about it.

Understandably, the sibling can be just as concerned and distraught as the SCI PP. Janet Penn recalls being very sad when her older sister, Julie, was home from the hospital. She was sad for a couple of reasons; including lack of attention and extra responsibilities she was not ready for. She stated, “I didn’t feel like I was in the family anymore, like they didn’t care about me anymore, cause more attention was being shown to Julie.” She shares how she coped with her feelings of sadness by stating, “I would just cry in my room or just get really angry . . . but when I would get around them [her family] I would calm down and try and be happy. Even though I was angry at them I didn’t want them to know.”

Janet referred to herself as the “little big sister” because of the added responsibilities of assisting with her big sister (SCI PP). Brittney Hubbard questioned what life would be like with her SCI PP brother, James, home. She stated, “I just remember thinking, what am I going to do with my brother, what is a 17 year old to do with no mobility, you know football star, basketball star, girl attractor magnet, what does a 17 year old boy like this do?” Sandra Smith was also unsure as to how to approach her brother, Mitch. Her main concern was not over-stepping her boundaries with him, and she states, “I didn’t want to offend him or upset him and make him feel like he couldn’t do something.”

Siblings often suffer deeply as they react to the new changes in all their lives and witness how distraught their parents are as the SCI struggles to fit into the new life pattern. It is as if the mind is in over drive as they are engaging in self-perception, self-evaluation and self-control in relation to their current situation, role reversals within the

home. Brittney Hubbard's brother, James, who was injured in a car accident, described it this way, "The damage of the injury has just eroded at your life. You go into a state like a drug-induced coma. You're running on auto pilot through everything, like what do I do?" Most of the time, the parents are completely oblivious to the concerns that the siblings are feeling and what kind of toll it is taking on them emotionally. Janet Penn, whose sister Julie was injured in a car accident, stated, "I always wanted my mom's attention because she was always there. I was a momma's girl, but it finally hit me. Her attention wasn't on me anymore. I was like. . . . uh . . . jealous." The siblings feel just as distraught as their family, but they hide their confused emotions. This may seem easy to forget since they are not the ones that are physically hurt. Rather than opening up, it is as if the self shuts down, internalizing all their feelings and harboring them.

Adjustment Phase: Siblings Serve as Support System

To understand what it means for the sibling to serve as the support system to the SCI PP, it is helpful to examine siblings interpretations of the dynamics of support within their families, especially how they view their parents having handled the impact of the SCI. Although the emphasis of this thesis is not on the parent's reaction to the SCI, I feel you cannot fully understand the sibling's relationship with the SCI PP unless you have some background of the relationship of the parent and SCI PP as well as the relationship of the parents with the sibling. The parents were usually understood by their children to be the ones with an opinion as to whether the SCI PP would walk or not. Not only did the parents wish to see the SCI PP walk, the participants in my study claimed, but the parents held on to this hope for years.

Participants in my study described their parents' reactions at the onset of the disability as either torn or hysterical. When the accident first occurred, most of the people I interviewed recalled their moms being in complete hysterics. The SCI PP might not have recalled witnessing this because they were sedated once they were in the hospital following the accident, but the siblings did remember the reaction of their mothers. Janet Penn recalled clearly, "My mom was really freaking out. She was just losing it." Once the SCI PP has recovered enough to enter a rehabilitation facility, which may take weeks or even months, parents cling to the hope that their child will leave rehab walking. At this stage, the parent is not ready to accept that their child will be in a wheelchair once outside of the hospital. Aaron Dunn, who was injured while riding a dirt bike, explained, "In their minds they pictured me on my feet and walking out of there. They weren't prepared like I had kind of prepared myself mentally. I knew I could be in this situation for a long time because I knew the way my body felt." While in rehab, the SCI PP is learning to use what they have to be independent. This does not always include standing up from their wheelchair and walking. Because this is what the parents want to see, they will push for more. Aaron said:

My parents wanted them to focus on getting my legs to work. They didn't understand that the rehab was really focused on what was working currently, not on trying to regenerate new things. My parents wanted them to work on things that weren't working. They didn't get it.

This is a common and natural mistaken concept of parents. For example, Robert Hooper, who was injured as a child when he fell out of a tree, recalled that his mother had one concept, and his dad had another. "My mom was gung-ho about getting me back on my

feet. My dad wanted me back on my feet, but at the same time he wanted me to be OK with however the situation turned out to be in the long run.” No matter how well-educated the family has been trained on how to handle the disability, it is hard for them to watch their child struggle.

It is understandable that parents, mothers in particular, suffer when they see their disabled child struggling. But this is a big part of rehab, learning to do things on your own again with limited mobility. Mitch explained:

My family hung around while I was at a rehab facility. The therapists were good at educating all of us about the injury and what to expect. Different people in my family had different opinions about it, about what they should and shouldn't do. My mom would always try and help me with everything where as it was more important to me to do it on my own for the sake of independence.

Many SCI PPs realized that they needed to struggle in order to become independent. For example, Aaron remembered:

I would struggle in the mornings to get ready, and then my mom would always rush in. They wouldn't allow me to struggle. They didn't understand that they needed to let me struggle; because that was the only way I was going to get better.

Parents must learn to step back and allow this struggle to take place. Moms that were protective of their children before the accident will be more over-protective later, as Julie Penn, who was injured in a car accident, notes, “Mom has always been a little over protective, she got worse after I became disabled.”

All but two SCI PPs reported that they adjusted to the acceptance of the disability quicker than their parents did. Some of the parents blamed themselves for the injury taking place. For example, for Timothy Rod, who was injured while playing high school

football, the accident happened 22 years ago, but his dad still felt responsible. “My dad blames himself for letting me play football, and he doesn’t get that was just me. My dad wanted something to blame on, but there wasn’t anything to blame it on.”

If the families had ever dealt with disabilities prior to the onset of the SCI, then they were quicker to move forward with the new normal. This was the case with James Hubbard, who was injured in a car accident. His sister, Brittney Hubbard, said:

They treated James the same after the accident as they did before it. Our family has lived with multiple disabilities, whether it’s our cousins or our aunts. We have had something that had to be taken care of at all times, so we grew up knowing if someone’s hurt, mentally disabled, or in a wheelchair, we accepted it.

The siblings recall their own reaction to the SCI as different from that of their parents. Even though they were not hysterical about the news of the disability, they were definitely just as distraught as their parents. During this distress, they knew one thing: they would support their disabled sibling no matter what they were going through. The siblings were concerned with ensuring the SCI PP still fulfilled the same qualities they identified themselves as prior to the crisis. The siblings witnessed their parents while they were in a state of panic. It was as if the only thing the parents could focus on was the SCI PP returning to a completely functioning able-bodied individual again. Julie Penn, who was in a car accident, recalls the difference between how her parent felt and how her sibling reacted to her current situation, saying, “My sister wasn’t so tuned on making sure I was going to walk out of there, my parents were.” The siblings knew not to burden the SCI PP with any other stresses, other than supporting them. The siblings had no problem seeing the perspective of the SCI PP by putting themselves in their shoes and reacting in

a way that is supportive rather than overwhelming the SCI PP. Unlike some of the parents, the siblings were never caught up in making sure that the SCI PP would walk again. For example, Robert Hooper recalls how his siblings reacted to the outcome of the disability by stating, “They kind of supported me in whatever I needed support with, and they weren’t trying to push me towards this or that.” Because of the amount of stress that the SCI PP was under already, the siblings were seen as more supportive of whatever the outcome would be, walking or not. Although the siblings were distraught of the situation with the SCI PP, they were quick to engage in the adaptive process. It was of great importance that the SCI PP feel as normal as possible regardless of the disability.

The siblings were also a witness to how the SCI PP reacted to the role discontinuity. The siblings could tell they were frustrated, sad, or angry. All the siblings wanted to do was emotionally support the SCI PP and treat them the same. Julie Penn recalls how her sister, Janet Penn, reacted to her when she was down about her current situation, saying, “My sister has always been real supportive of me. When she sees I’m depressed she tries to talk me out of it.” All the siblings realized nothing changed about the SCI PP except for the fact that they were in a wheelchair. They still were the same person. They still acted the same, therefore they would treat the SCI PP the same. For example, Janet Penn, sibling, recalls how treating her sister the same way made her feel better:

Some of the family members were like, “Oh I’m so sorry,” or [they would] be all sad, or try and do a lot of things for her and I could see that upset her so I would be like a big sister towards her, make jokes about something or try and cheer her up. That kind of helped her out, made her

feel like somebody, it made her feel the same. I was like, “she is still the same person, so I will treat her still the same.”

It was natural for the siblings to treat the SCI PP as they always had. Bobby Wright gives a clear example of this when he refers to his sister, Analisa Wright, who was involved in a car accident, saying, “I don’t see her as a person with disabilities just a person that can’t use her legs. I’ve always treated her the same.” Treating the SCI PP the same is a way for the sibling to remind their SCI PP that they are still the same person regardless of the situation. The sibling not only was there to support the SCI PP emotionally, but to help out with anything they needed. Although I did not interview the parents, from the siblings account, it was apparent that they quickly adapted to the adaptive process with their SCI PP.

Siblings began to miss the role that they had prior to the extra responsibilities taking care of their disabled sibling. There is a sense of obligation to help out. Janet Penn reiterates the same feelings Natasha Rod had when her SCI sibling returned home, saying:

Sometimes I feel like I’m supposed to be here, especially now since I’m out of high school and in college and I have friends, I kind of want to hang out with them, but sometimes I have to cancel plans cause I have to be here so I kind of feel like I’m pressured.

This, of course, is not the intent of the SCI PP. As a matter of fact, there is a feeling of regret from the SCI PP that their younger siblings had to grow up fast by taking on these extra responsibilities. For example, Timothy Rod explains how this made him feel when his younger sister had to help out more due to his injury:

I will say Natasha had resentment because she went from being 12 years old with attention and then it’s all back on Timothy. I still regret it, I didn’t

need it, I was 18 years old and about to move out to college. Instead she didn't get her time to shine. I always regret that they had to grow up quicker.

The SCI PP finds it unfair that their younger siblings had to grow up so fast. The last thing that they wanted is a role reversal; they desired life to continue as it was prior to the accident.

Not only did the siblings have extra responsibilities, but they did not want to express truly how they felt during this adjustment phase. The siblings expressed to me that they feel this way because they do not want to burden their parents with anything else. They also do not want to hurt the SCI PPs' feelings. Natasha Rod clearly remembered how she felt about her brother Timothy Rod's situation, saying, "Mom and dad had a lot on their plate. It was like, don't burden them, they have so much on their plate. I learned to figure it out on my own." This makes the sibling grow up faster. They had to deal with feelings brought on from a tragedy at a young age. This is a reason I say the mind is in overdrive, the sibling must evaluate and control how they act in difficult situations simultaneously. In this case, the situation would consist of the household and the roles between parent and the SCI PP. The injury results in a combination of extra responsibilities and dealing with feelings alone. This leads the siblings to mature at a quicker pace than what they would have liked and gain a quick reality of lessons that are normally learned later in life.

During the adjustment phase, all the siblings in my study experienced their parents caught up emotionally with the physical disability. The siblings witnessed how the parents and SCI PP reacted to the disability. Their reactions led the sibling to want to

do nothing more than support their sibling. This is something that was natural for all the siblings. What the siblings did not see coming were the extra responsibilities the injury could bring. In the end, it does make the sibling mature quicker.

Independence Leads to “New Normal”

A new normal, from the perspective of the sibling for the SCI PP, was that the SCI PP was strong willed in their drive to resume to activities once enjoyed prior to the accident. For the SCI PP this meant role making by finding adaptive ways to be active members in society (work, school, hobbies and having a family). According to the siblings, a positive outlook and independence were recurring themes when it came to what helped the family overcome the initial shock of the disability. Natasha Rod explains how her brother’s ability to be strong-willed helped the family move forward with the disability, saying, “The root is Timothy, and if it was anyone else I don’t think the outcome would have been the same. It had to take someone very strong-willed and very outspoken like Timothy.” Having a strong will ultimately will help get you toward your goal of independence. Julie expresses how faith and being positive helped her family cope, saying, “Well our faith really helped. Also staying positive helped the family stay positive.” The ability of the SCI PP to be positive in this situation is contagious, leading other members of the family to feel the same way. Julie Penn’s sister, Janet Penn, recalled how it helped her family, saying, “She wasn’t down, so once they saw that she was ok they were ok with it. A lot of people find her as an inspiration.” Many people feel like it is not easy to stay positive through such a life altering experience. When family members witness this, it makes the experience an uplifting one.

Once the family members are able to accept the fact that the SCI PP is confined to the wheelchair, they are able to also move forward. At this stage, a new normal for the sibling means being open minded about the capabilities of individuals with disabilities, not taking life for granted, being more cautious and closer to the family. April Dunn, whose brother Aaron was injured while riding a dirt bike, explains this by referring to it as a new normal, saying, “At first we thought he was going to walk again and we tried all these things, it has helped with his coordination. Once we adjusted to it, it becomes normal.” How long it took the SCI PP to become independent again determined how soon the family was able to accept the injury as a new normal. Robert Hooper, who was injured as a child when he fell out of a tree, explained how his independence helped his family realize what he was capable of, saying, “Seeing me independent was the biggest help.”

Faith in a higher power was also a recurring theme. Sandra explained how the family’s faith helped with overcoming the tragedy, saying, “We’re a Christian family, being involved with a church helps. It helps to have faith in your life when you go through something traumatic.” The ability to have faith in a higher power allows one to know that the situation will work itself out for the best. Bobby Wright gave a great example of witnessing how having faith helped his mom when she first heard about the impact of the disability on his sister, Analisa Wright:

When my mom was sitting in the hospital outside my sister’s room, she was freaking out. She did not know what to do at all; she was in so much shock. She said she just kind of sat there and handed it to GOD. After that she just kind of felt like everything was going to be ok.

At first, the onset of the disability can come across as overwhelming. There are so many unanswered questions. When the family has faith in a higher power, their mind-set allows them to have faith that everything will work itself out.

Discussion: Outlooks on Other SCI and Career

What is learned from the crisis can have an impact on the sibling's future outlook and what they would consider a "new normal"; they do not underestimate what it means to be identified as someone with a disability, and they would consider dating someone with a disability or working with others who are disabled.

After the onset of the disability, the SCI PPs and the siblings both had more of an appreciation for individuals with disabilities. They respected them more. Part of this is due to the realization of how much it takes to overcome such a tragedy. As Natasha Rod explained it "When I see someone with a severe disability, I think, 'What a warrior!' I used to think to myself, 'What's wrong with that person?'" Natasha added, "Once you live through it, you realize what it takes to be independent."

Julie Penn agreed. "When I see people in wheelchairs, I understand that it takes a lot of strength to keep going." Sandra Smith recalls her feelings when she first saw someone who was disabled, saying, "I knew what paralysis was, but I never understood that even though he is paralyzed, he can do everything a normal person can do if he has certain modifications."

A couple of the siblings indicated how they would now consider dating someone with a disability. April Dunn recalls how her outlook has changed with respect to disabled people, saying:

When I see someone in a wheelchair, it changes my perspective. Let's say I would date someone in a wheelchair. I'm not uncomfortable to talk to someone in a wheelchair anymore, but it is not something that is of the unknown anymore.

Those who are disabled will often identify with others who have had to meet similar challenges. They can give each other emotional support and understanding. Analisa Wright says it this way: "We have certain things in common, but we're not stereotypes." Each person in the handicapped community can truly empathize with other disabled individuals.

Another recurring theme among almost all the individuals interviewed was their strong desire to give back to the world and to work in fields that allow them to help other people. Some of the favorite careers included physical therapy, nursing, special education, and financial advising. Natasha Rod is drawn to nursing because, as she states, "I have discovered how much I can handle, and I understand it and I feel passionate about it." All of the interviewees felt like they could also impact others by sharing their experiences. Aaron Dunn chose finance as his field.

I went into this area because I was sure that I could impact people's lives. I could share my experiences and show how financial disasters could happen when someone becomes disabled. The handicapped [person] needs financial planning, including insurance. I think I am going to be able to change people's lives.

Some of the SCI PPs were working on different college degrees from those they had initially hoped to earn. Career paths often have to be changed because of the physical disability. Such was the case with Mitch Smith, who explained that he had wanted to work in law enforcement but the onset of his disability forced him to take a desk job. "I went to Sam Houston and got my criminal justice degree, but I didn't do anything with it;

the degree just sits on my wall. I do real estate now, office job, 9-5 for the most part.” Regardless of the type of career that the individual changed to, they were still leading independent, successful lives.

All of the individuals interviewed felt as though the accident, in one way or another, impacted their lives for the better. “I think this accident made me have to take a step back, and it really put me in check,” Aaron Dunn said. “I realized I had to respect life in a different way because my life was almost taken from me. It’s been a blessing in that it has changed how I look at life; it’s made me grow up.” Most of the individuals said they cannot imagine where they would be, had the accident not happened. James Hubbard reiterated Aaron’s sentiments. “I think it slowed me down mentally, to stop and kind of realize I’m not invincible and I do have to take of myself. It makes me realize that I got other things to live for, that I can’t just do whatever I want to do now.” They now see how fast life can be taken away or forever altered. The important thing now is to live life to the fullest and surround yourselves with those you love.

Another reason why they believed it impacted them for the better is that they can now impact others’ lives. Robert stated, “I think for the better, I’m able to make an impact on a lot of people. I don’t really know what my life would have been.” Impacting peoples’ lives makes you realize that not everyone is able to have a positive outlook and overcome such a tragedy. Therefore it is up to the SCI PP to again educate others by proving that life does not end just because you have a disability, but that good things can come from a negative situation. As for the siblings, they too can educate others who have not encountered someone with a disability.

Chapter 5

Discussion and Conclusion

How does the sudden impact of a disability within the immediate household affect the siblings? In my study, I learned that an SCI has a strong impact on siblings. In reference to self, identity and roles I learned that the self is in overdrive while the siblings are learning how to identify with a disability. In other words, the sibling have a lot in their mind as they try and figure out the appropriate way to react during a very sensitive time in their families lives. I also learned that their roles are subject to stress. There were five ways this impact was most often discussed by my study participants.

First, the siblings discussed their initial feelings of sadness and shock when learning of the severity of the incident. Second, the siblings all shared how they witnessed everyone's reactions to the SCI PP injury and noticed how this made the SCI PP feel. The siblings noticed that the SCI PP appeared sad and overwhelmed by the reactions of others; therefore, the siblings felt that they needed to uplift, support, and encourage the SCI PP. At this stage, the self is engaging in reflexive behavior by observing, planning, and acting out what they perceive to be of help in uplifting the SCI PP while he or she adjusts to the injury. Third point, the siblings, who were all younger than the SCI PP, referred to themselves as having to take on the role of older sibling. During the state of role reversal, there is a sense of role obligation on behalf of the sibling. The SCI PP on the other hand is dealing with role discontinuity—which Michener et al. (2004) defined as, “when the values and identities associated with a new role contradict those of earlier roles” (p. 76). Janet Penn referred to herself as the “little

big sister,” while Natasha Rod recalled her transition to the role reversal by stating, “ I went from being not the little sister so much; I got to see so much stuff on my brother that I would have never seen.” While the siblings undertook the role reversal, they were suppressing their feelings. The siblings were not only assisting with the caretaking of the SCI PP and acting as their support but also witnessing things they thought they would never have to witness, such as involuntary bowel or urine movement or uncontrolled reflexes. When the interaction between the siblings was complementary prior to the disability, there tended to be a role reversal when the SCI PP was the older sibling, causing the younger siblings to act as a third parent. There is a sense of obligation to helping the SCI PP while a sense of sadness, not only for the SCI PP but also dealing with a change in the relationship with the parent. The role obligation comes with role conflict because they are acting as older sibling while still trying to play the role of younger sibling. The sibling does this so they can make the SCI PP feel as if they are still looked up to as the older sibling. The sibling is saddened because their role as younger sibling has been diminished. Despite all this, these narratives bring me to my fifth point. The siblings all created a stronger bond with each other after the accident. In my study, it became apparent what types of phases the family went through after the crisis.

The realization of the disability produced a period of role confusion for everyone. This is the beginning of the adjustment phase. This does not come easily. The reality of identifying with a disability created stress and fear; however, through interaction with the family, the self-process of imagining one’s self from the perspective of others allows individuals to evaluate and plan, which helps reduce this fear and stress. They also begin

to understand what steps need to be taken to resume a “normal life.” Hence, role-making is initiated and role discontinuity begins to diminish. Initially, the SCI PP does not identify with the disability. This was apparent during this adjustment phase, the SCI PP feared the unknown of what it meant to be disabled. From what the SCI PP recalls prior to the accident, the status of having a disability was not promising. This was an example of the stress they felt from role discontinuity.

The SCI PP also worried about how their siblings viewed them. The disability becomes an object to which the self can evaluate and attach more or less meaning. The siblings, on the other hand, served as a foundation or reminder to the SCI PP that they are still the same person as prior to the accident. This is an example of how your identity is a part of your past, present and future. The disability does not necessarily change how your family identifies you. After the accident, the SCI PP is still identified by the sibling as the same person they were prior to the accident. The siblings in a sense, no longer identify themselves as taking the role of younger sibling, as they are now acting as older sibling in a complimentary fashion to help the SCI PP as they adjust to the disability. According to my study, the siblings served more as a support system to the SCI PP. Rather than being overbearing like other loved ones, primarily parents (as indicated by the siblings in the study), siblings gave the SCI PP space and wanted them to feel as independent and normal as possible. They wanted to ease the role conflicts and role discontinuity of having a disability. Rather, the siblings reminded the SCI PP of how they previously identified them. The siblings embraced the adaptive process quite quickly. They were not consumed with ensuring the SCI PP would make a full recovery by walking. Rather

siblings focused on keeping the SCI PP's spirits lifted during the process of rehabilitation. This is the "right thing" to do in their eyes, as it fulfills their roles of sibling, which involves, caring, supporting and loving.

I can speak to the roles that younger siblings had to take on due to my own personal experience and my data. All the siblings I interviewed were younger than the SCI PP. According to my data, the siblings were not only emotionally impacted, but a few felt as though they were robbed of the quality time they used spend with their parents. This is a product of the role conflicts of parents (according to the siblings and SCI PP) who were overwhelmed by working and attending to the SCI PP. In addition, siblings had to grow up faster by taking on the role of the older sibling. This was not an option, rather what they felt as an obligation.

Interaction in this study was understood to consist of two styles: complimentarily and reciprocity. In my study, all the SCI PP's were the older siblings, therefore prior to the accident they took pride in the role of interacting in a complimentarily fashion. So, for example, the SCI PP's acted as a third parent in a way by reprimanding, praising and looking after the younger siblings. They enjoyed their identities as the older sibling. After the accident, roles reversed, requiring the younger siblings to adapt to the needs of the older sibling in a complimentarily fashion. This was because of the temporary role discontinuity of the SCI PP. The siblings were also in a sense reciprocating the same types of actions and responsibilities the SCI PP had relative to the sibling prior to the accident. The only difference is the sibling was not ready to step into such big shoes and act as the older sibling. Thus, siblings had to grow up faster. This was primarily because

they suddenly received less attention or assistance from the parents or the older sibling (if the older sibling was the SCI PP as in the case of my study). Instead, the parents' undivided attention was on the SCI PP and the other sibling did not want to feel as if they were burdening their family with their concerns. They saw this as the best way to reduce less stress on the family. This entailed more responsibilities, such as chores, and being more independent, for example not relying on the parent or older sibling for day-to-day things such as meal preparation or self-care. The other side to this is that the younger sibling acted as an older sibling to the SCI PP by encouraging them and helping them with their day-to-day needs.

The siblings also supported the SCI PP through the adjustment phase, while suppressing their own feelings. There was a role reversal in the sense that younger siblings played the role of older siblings. This was due to the extra responsibilities of assisting the SCI PP and encouraging them. Although the non-SCI sibling was taking on abrupt role changes, their feelings were dealt with in solitude. Siblings saw the emotional turmoil placed upon the SCI PP and parents, and they did not want to over burden their family members with their own concerns. It was evident through all this that the family is a strong unit and is able to overcome something that would never be wished on another family: a life-altering event that affects life physically for one member of the family and emotionally for the dynamic of the family. The key here is that the family does adjust with what is now a new normal. The occurrence of the disability ultimately brings many families closer, creating a strong bond. But the road can be a bumpy one.

Over time, families develop stable patterns of roles and interaction that members work to sustain. But when the situation presents itself, the family is forced to assess and adjust in order to get back on track. In the process, primary attention is given to any individual who has been directly impacted by a disability, while their siblings are adjusting, trying to figure out things as they go. What has been learned from this study is that while the siblings are coasting, they are dealing with the loss of their parent's attention, the changes in their injured siblings, and trying to figure out what they can do to help, all while feeling like they should not burden their parents with their concerns. The siblings in this study demonstrated interpersonal competence in supporting SCI PP, while the parents, according to the siblings, were consumed with the medical treatment of the SCI PP and the disability. Initially there was a sense of fear for the goals of the SCI PP in the sense that some of the roles the SCI PP previously assumed were now out of their reach. The family never wavered on identifying the SCI PP as the same individual; merely on what the future would hold when it came to goals and aspirations of the SCI PP. Identity as a disabled person consists of understanding how society views the disabled and reacting in a way that would allow them to continue to feel independent and productive. The siblings never doubted the capabilities of the SCI PP, while the parents initially had a harder time realizing this. I hope this study will help to enlighten the family, open their eyes to the effects of a disability, on all family members, and provide parents with insight as to how the siblings feel and what the SCI PP really wants from their family.

Siblings are witnesses to their parents' reactions to the disability and the SCI PP. The siblings are trying to deal with the life-altering event just as their parents are. They see and hear everything that is going on. Natasha Rod, whose brother Tim was injured while playing high school football, recalled the toll the injury took on her mom when she talked about how visibly stressed she was. Natasha stated:

I remember my mom had brown hair and she suddenly had grey hair, like she aged so much in that month and half. I remember thinking 'mom what's going on with your hair?,' but I now know it was stress . . . I remember her being wound tight, like kind of quick to anger.

Not only do the siblings visually see the impact of the injury on the parents, but they also hear adult conversations about financial problems. Natasha also recalled, "My dad worked a lot more . . . I remember them being worried about money and bills, I know his work was very good in the sense of insurance stuff, but not good enough and stuff [i.e. bills] just kept coming in." In most cases, either the parents worked longer hours to maintain medical bills or to compensate for one of the parents quitting their job to take care of the SCI PP. In other cases, if it was a single-parent household such as Janet's and Julie Penn's household, the parent not only worked long hours, but prior to and after work focused their attention on ensuring the SCI PP was bathed, fed, changed, and situated. This left less time for the sibling.

Role conflict was apparent for many of the parents as expressed by the SCI PP and sibling. Aaron Dunn's mom for example, quit her job to stay home and take care of him; ultimately this can contribute to the stresses the SCI PP feels and the parent feels, causing them to take it out on each other. Aaron recalls, "I mean, you get frustrated, so

you take it out on the people you love. So me and her bumped heads a lot, we would argue and fight a lot. That was just out of frustration with coping with the new means of life.”

Brittney Hubbard was 12 when her brother James was injured in a car accident. She brought up another thing as to what parents might not realize during the initial injury, which is a lack of supervision and discipline for the sibling. Brittney stated, “Well, a 12 or 13 year old with no mom or dad to watch her, you kind of go buck wild.” At the time she was aware of the situation because she added, “it was because they couldn’t be there, there was a more important situation at hand.” The stresses of the parents include communicating about the financial bind they may be in due to the medical bills, their concerns about getting the SCI PP to walk again, and even disagreements between the parents about how to handle the situation. Because of all this, the siblings are afraid to burden their parents with any other concerns. Therefore the sibling’s feelings and concerns are neglected. It does help when the younger sibling has other siblings that are closer in age to vent to. One way or another, the sibling wants and needs to, vent about how they feel.

Some advice given by the siblings I interviewed was for the parents to be open with them. Natasha advised parents to do the following:

Do the best you can to pay attention to the ones that did not get hurt and tell them the truth. Don’t hide what’s happening, ‘cause even if they’re real young, maybe you have to bring it down to their level, be as fully honest as you can, cause they will find out anyway. Just not disclosing everything, I remember being so scared anyone could die or get hurt, I’m not saying it wouldn’t have gone away but at least I wouldn’t have always wondered what they are talking about. Just be fully honest with every part,

because kids are smart and give all your kids more credit for what they can handle.

An accident is such a chaotic time in life, it is helpful to try to not stress about the disability itself. This sounds easier said than done. But if the family can focus on one day at a time rather than overwhelming themselves with something that might be out of their control, the situation will work itself out. Brittney Hubbard, the sibling to James who was injured in a car accident, gives advice for families to:

Grin, bear it and keep your mouth shut because it will all be ok, everything has a way of working itself out. Every family is different, everyone's emotions and actions are different towards the situation, but if you throw everything you got into the situation, all your emotion, all your panic, all your chaotic thoughts, it's not going to help the situation at all, it's not going to help move forward with a disability in their life, it's not going to help if all your thinking about is you, you're not thinking about them, they just want to move on. The only way to live life is to get over things, and if you never overcome it or have a blocked mentality then you or your mom or dad will never get over it.

The main point is that the family wants to move forward with their life as soon as possible. Advice that the siblings would give families with reference to the SCI PP is to treat them the same. In my study it was apparent that the siblings still identify the SCI PP as the same person they were prior to the accident. They are identified as having a disability. How they identified themselves in the past, carried into their current situation. Therefore, siblings continued to interact with SCI PPs in the same manner they did prior to the accident. The roles created prior to the accident created a firm foundation and reference as to how to treat each other in a time of crisis. These roles create a sense of normalization by allowing the participants to revert back to interacting the way they did prior to the accident. The siblings in my study advised families that if guidance is needed

to get people who have experienced an SCI back to an independent life, then help them out. Sandra's advice was, "When you need to cry, cry, but know life is not over for the family member that got hurt. Life is just beginning in a new way. But at the same time he is the same person, it's just a different way to live." When it comes to independence,

Robert stated:

Push them as much towards independence, regardless of walking or not walking, push them towards independence, don't cater to the dependencies, don't let them fall into that trap. And also push them to be social, it's really hard to adjust when you have the disability right off the bat, being social doesn't come easy sometimes. So push them as much as possible to be social.

Many of the communication and interaction patterns prior to the onset of the disability helped the family maintain a certain balance.

The SCI PP's take on being disabled is the need to get back to an independent life as soon as possible. As soon as this is done, the feeling of role discontinuity subsides, and there is no longer stress caused by role strain and role conflicts. They do not want to be pitied or looked down on; rather they want to be seen as a perfectly functioning person. The mood of the SCI PP definitely had an affect on the family in the study. The SCI PP and sibling acknowledged the SCI PP's attitude as a contributing factor in being able to move forward with the disability. When the SCI PP was positive while trying to maintain their independence the process was a lot easier on other members of the family.

In discussing how he would like others to treat him, Timothy Rod's advice was:

The one thing my brother sister, mom and uncle, they weren't going to pity me. They were going to treat me the same way: you're still my son,

my older brother. Don't let the disability change them. Sure, physically it's a change but that's the only way. It should not be emotional. Continue to treat them way you did before, be there to support them and if the relationship was bad hopefully you learn real quick this is a disability and everything can be taken away from you in an instant, and cherish what you have. If you do it the right way this disability can bring out some amazing things for you.

In sum, the incident is tragic, but life does move on and gets better. Part of helping other families get through such a life altering event, in the end, is to open up and share with others their experience.

There are some exceptions to how families deal with the sudden onset of a disability. When the family members have been around other disabled people, especially disabled family members, they are better able to grasp the idea of the disability. Because of this, they know that the disability is not an end to being a productive member of society. The sibling bases this on how they identify with the siblings prior to the disability.

Communication does go a long way. Depending on how the family interacted prior to the accident, communication styles impacted how or if the crisis was to be addressed amongst the family members. It was evident when the communication style was closed, that family members harbored feelings of guilt and resentment. This was the case for Janet Penn. She recalled how she dealt with her suppressed feelings by stating:

I barely got any attention at all or really noticed. Um kind of at times I felt neglected, like they didn't notice me, slightly depressed. I don't like bringing that type of mood towards them so I would hide it and pretend like I was ok.

She continued by adding:

I would just either cry in my room or just get really angry and like destroy something I had, or try and hurt myself in a way just to go through the pain. But like when I would get around them I wouldn't be that way, I would calm down and try and be happy. Even though I was angry at them, I didn't want them to know that.

Prior to the accident, Janet was a quiet person and did not express herself much according to her sister, Julie Penn, "She's kind of shy."

On the other end of the spectrum, when family members were open about their feelings prior to the accident, this carried over to how they communicated about the disability after the incident. Take for example the Smiths. According to Sandra Smith, "my family is definitely some talkers, we talked about it. I don't remember anything specific, but just trying to figure things out how was life going to be now. We were open about it for sure." She continues by stating that her mom was more of the "talker" in the family but she did have a way of communicating about the disability by stating:

My parents finally explained to us after the first few days what the injury was and what it meant but once Michael got home, we got him a room that was handicap accessible. Family helped us to help him. My mom was the one that was always there, my dad lived an hour away from home. My mom was the one that was there for everybody. I don't remember having any deep conversations with my dad about the injury or anything, but if I had any questions I would go to my mom.

Not every member may be open to discussing what the crisis means to them and how it impacted them, but a large part of this has to do with how the individual was prior to the accident.

The siblings had a different outlook for individuals with disabilities. They now knew how to perceive someone with a disability; they did not view the status as one to be looked down on. Siblings were no longer afraid or uncomfortable about being around

someone who is disabled. This is because they now identify with someone who has a disability, they are now fully aware of the capabilities of a person with a disability and how strong they are to be able to overcome everyday obstacles. Because of witnessing their SCI sibling, they had a new-found appreciation. It changed how they identified themselves. Due to this experience, the siblings would now consider dating someone in a wheelchair. They felt more comfortable in their encounters with someone with a disability. They were more educated about what it means to be disabled. The impacted family members also considered careers that would enable them to help other individuals who are disabled.

In summary, this study provides insight into how a family protects themselves from crisis. It also helps identify what the individual deals with in terms of how the self perceives a situation such as a crisis. The stresses caused by role discontinuity, role conflicts and role strains. The sibling is more likely to deal with role conflict and role strain due to feeling obligated with stepping in and handling multiple roles. The SCI PP is more likely to feel overwhelmed and stressed with role discontinuity due to feeling like their dependence has been stripped from them and feeling inadequate as role of older sibling. When a crisis happens, the family reverts back to interaction styles practiced prior to the accident. Although the parents were not interviewed, based on the SCI PP and the sibling interviews, it appears that the siblings had an easier time transitioning to the crisis compared to the parents. The bonds created by roles and the interaction patterns that come with these roles created a firm foundation to revert back to during such a chaotic moment brought on by a crisis. In addition, how the SCI PP identified him-or

herself prior to the accident remained into their current situation. Although unexpected, the siblings who were all younger than the SCI PP stepped into the role of older sibling. The ability to step into this role was reciprocated. The siblings knew how emotionally distraught the SCI PP was, so they wanted to be there for them to help while at the same time encouraging and reminding the SCI PP they were still the same person. The siblings were an important influence on the “me” of the SCI PP, while the SCI PP is simultaneously an important influence on the “me” of each sibling. Although this sounds like an easy process, it is not. Siblings harbored feelings of concern, sadness, and at times, resentment. The SCI PP may heal and move on with their lives, while the sibling’s suppressed emotions may never have been addressed. In order to move forward from such a tragic event and emotionally heal, it is highly important to keep in mind that although the family member who has been directly impacted by the crisis is undergoing a life altering event in their lives, so are the siblings who essentially are a shadow to the affected sibling.

Limitations of Study

In future research, two aspects could be included that were not in this study: the birth order of the siblings and the level of the paralysis. The level of paralysis makes a difference in how dependent an individual would be on family members. The higher the level of disability, the more reliant they are on family members. In regard to the birth order, there are a couple of suggestions. The first is to focus on the youngest sibling; they seemed to be most affected when it came to the relationship with their parents. The second is to interview more than one sibling of each participant in order to gain a better

understanding as to whether or not different ages have different outlooks on how the disability affects them and their roles within the family. Finally, because the family is a system level unit, it is important to get first-hand accounts from those who constitute every part of the unit. Thus, it is vital that future research studies integrate the viewpoints of parents, and, in some cases, grandparents in order to draw richer conclusions about families as a whole.

Appendix A
Interview Guide for SCI Participant

Prior to Disability

1. How old are you?
2. Can you tell me who is in your family?
Probes- How many siblings do you have? Are you the oldest or youngest?
How old are your other siblings?
3. Prior to your accident, what was your relationship like with your siblings?
Probes- Did you all spend a lot of time together?
4. What types of activities would you and your siblings like doing together- when you were growing up?
Probes: What were some rules growing up in the household? Were your parents adamant about how you and your siblings got along? If you did not get along how would they discipline you? Who would normally be the one to discipline you?
5. Can you tell me how your relationship was with your family prior to the onset of the disability?
6. Is there a time that you recall seeing or interacting with someone who had a physical disability?
Probes: If so, what was your reaction? How was the disability explained to you? What did this mean to you, or how did it impact you?

Onset of disability

7. Can you tell me how you became disabled?
Probes: How old were you at the time of the accident? (If the PP lived outside of home when accident occurred, would ask, did you have to move back home for a certain amount of time after the accident?)
8. Can you tell me about some of your initial feelings, or how did you view yourself?
9. While undergoing your most intense treatment (within first couple of months of accident), how was your relationship with your family?
10. What was communication like about the disability amongst family members?

11. How did your parents react towards the disability?
 - a. Probes-what were your thoughts towards their reaction?
12. How did your siblings react towards the disability?
 - a. Probes—what were your thoughts towards their reaction?
13. Did your relationship with your siblings change from what it had been before?

After Disability

14. How was your parents relationship with your siblings after the disability?
15. What was your relationship like with your parents after the disability?
 - Probe-In what ways and how is it different, if any?
16. Do you spend time with your siblings?
 - Probe-What types of activities or things do you and your sibling's do for fun?
17. How well has your family overcome the initial shock?
 - Probes: What do you think helped the family overcome the initial shock from the accident, and continue on with life with the presence of the disability?
18. Would you explain if having the SCI has changed your perspective about other individuals who have a SCI?
 - PROBES—How about how your family views the SCI
19. How do you think other people look at people with disabilities?
 - a. Probes-How does this make you feel?
20. Has the accident had an influence on your career choice?
21. How has the accident impacted your life?
22. Has the accident influenced how you think about disabled people?
 - Probes—if so in what ways? Dating potential?

Is there anything you'd like to talk about that we haven't yet discussed?

Interview Guide for SCI Sibling

Prior to Disability

23. How old are you?

24. Can you tell me who is in your family?

Probes- How many siblings do you have? Are you the oldest or youngest?

How old are your other siblings?

25. Prior to NAME (sibling with SCI)'s accident, what was your relationship like with your sibling?

Probes- Did you all spend a lot of time together?

26. What types of activities would you and your siblings like doing together- when you were growing up?

Probes: What were some rules growing up in the household? Were your parents adamant about how you and your siblings got along? If you did not get along how would they discipline you? Who would normally be the one to discipline you?

27. Can you tell me how your relationship was with your family prior to the onset of the disability?

28. Is there a time that you recall seeing or interacting with someone who had a physical disability?

Probes: If so, what was your reaction? How was the disability explained to you? What did this mean to you, or how did it impact you?

Onset of disability

29. Can you remember when your sibling became disabled?

Probes: How old were you at the time?

30. Can you tell me about some of your initial feelings when you found out your sibling was disabled?

31. While your sibling was undergoing their most intense treatment (within first couple of months of accident) how was your relationship with your family?

32. What was communication like about the disability amongst family members?

33. How did your parents react towards the disability?
 - a. Probes- What were your thoughts towards their reaction?
34. How did your siblings react towards the disability?
 - a. Probes- What were your thoughts towards their reaction?
35. Did your relationship with your disabled sibling change from what it had been before? If so, how?

After Disability

36. How was your parent's relationship with your (sibling with SCI)?
37. What was your relationship like with your parents after the disability?
38. Do you spend time with your siblings?
 - Probe-What types of activities or things do you and your sibling's do for fun?
39. How well has your family overcome the initial shock?
 - Probe: What do you think helped the family overcome the initial shock from the accident, and continue on with life with the presence of the disability?
40. Would you explain if the SCI has changed your perspective on other SCI?
 - PROBES—How about how your family views the SCI
41. How do you think other people look at people with disabilities?
 - Probes—how does this make you feel?
42. Has the accident had an influence on your career choice?
 - Probes—if so in what ways?
43. How has the accident impacted your life?
44. Has the accident influenced how you think about disabled people?
 - Probes—if so in what ways? Dating potential?

Is there anything you'd like to talk about that we haven't yet discussed?

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Biographical Information

In 2008, Vanessa received her bachelor's in sociology with a minor in psychology. Her areas of research interest are the family of people with disabilities and people with disabilities. Her future plans are to continue mentoring people with disabilities and educating their families on what to expect when they are suddenly impacted with a crisis, such as acquiring a spinal cord injury.