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The Description of Life Experiences of a Person with Pediatric-Onset Tetraplegia During His Upper Teen and Young Adult Years

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During His Upper Teen and Young Adult Years

By

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for the degree of
MASTER OF SCIENCE
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DEDICATION

This thesis is dedicated to my husband,
Scott Yarberry

And

My family,
Rodney Edmondson
Celisa Edmondson
Blake Edmondson

who have always supported me in all my endeavors and educational experiences

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Abstract

The purpose of this narrative case study was to understand how a young man with pediatric-onset tetraplegia described his life experiences during his upper teen and young adult years. Data was obtained through two individual semi-structured interviews and observations. Interviews were conducted, recorded and transcribed by the primary investigator at the home of the participant. The participant provided information about his life including his experiences with family, friends, and healthcare providers. Six themes that emerged from the data included I a*lways have someone with me, I'm not easily broken, I'm stubborn, I've made it the best I can make it, I'm just like everybody else,* and *Right now it's about me doing what I want to do.* Results showed that the participant and his family viewed his experiences as typical, but they were actually rather unique. This included never being able to spend time alone, having to use adaptive equipment or transportation, and having a positive attitude about most situations including his ability to find ways to make things work.

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Chapter 1

Introduction

According to the National Spinal Cord Injury Statistical Center (NSCISC, 2013), the number of people in the United States with a spinal cord injury ranges between 238,000 and 332,000 with approximately 12,000 new cases occurring each year. Of these injuries, over 80% are males with the main cause of injury being motor vehicle accidents (MVA) followed by falls and acts of violence.

There are two different classifications of a spinal cord injury: tetraplegia and paraplegia. Tetraplegia is characterized by a “loss or impairment in motor and/or sensory function in the cervical segments of the spinal cord resulting in functional impairment in the arms, trunk, legs, and pelvic organs” (ASIA, 2000). Paraplegia is characterized by the “loss or impairment in motor and/or sensory function in the thoracic, lumbar, or sacral segments or the cord resulting in impairments in the trunk, legs, and pelvic organs and sparing of the arms” (ASIA, 2000). All spinal cord injuries are different even if they occur at the same level. This is mostly due to the type of injury sustained, and whether it is a complete or an incomplete lesion. A complete lesion is categorized by the “absence of sensory and motor function in the lowest sacral segment” (ASIA, 2000, p. 7). An incomplete lesion is characterized by “partial preservation or sensory and/or motor function below the neurological level including the lowest sacral segment” (ASIA, 2000, p. 7). The most frequent level of spinal cord injury reported is incomplete cervical lesions (tetraplegia) at 40.6%, followed by 11.6% of complete tetraplegia. Incomplete paraplegia is 18.7% and complete paraplegia is 18%.

Incomplete tetraplegia numbers are rising while complete paraplegia and tetraplegia are decreasing (NSCISC, 2013).

Persons with spinal cord injuries have varying levels of independence. People with paraplegia are typically independent in most areas of self-care and mobility. Those with tetraplegia tend to require assistance in most areas of self-care, such as upper and lower body dressing, bladder and bowel management, and bathing. Persons with tetraplegia may also require more medical attention. Individuals with lesions at levels between C6 and C8 typically have a tenodesis grasp, defined by Radomski and Trombly Latham (2008) as the "passive opening of the fingers when the wrist is flexed and closing of the fingers when the wrist is extended" (p. 1172). At level C5, they usually have bicep and deltoid strength which will allow some arm movement, though they will need assistance with grasping. Persons with injuries between levels C1-C4 usually require external support to aide with breathing and are paralyzed from the neck down.

Surviving spinal cord injury at levels C1-C4 is less likely to occur as life expectancy is lower than other spinal cord injuries (NSCISC, 2013). The NSCISC found that the average age of life expectancy for a person whose injury occurred at age 20 and survived the first 24 hours is approximately 35.3 years old while those who are 20 and ventilator dependent is approximately 18.6 years old. For those who acquired the injury at 20 years of age who survived a year after, the life expectancy is 36.6 years, and for those who are ventilator dependent it is approximately 24.9 years (NSCISC, 2013). Given these statistics, there are a limited number of people with injuries between levels C1-C4 available to participate in research, making this population understudied.

Researchers and medical professionals do have knowledge about the functional abilities of individuals with C1-C4 tetraplegia. Researchers have examined a wide variety of topics related to tetraplegia, including autonomy in upper level spinal cord injuries (Van de Ven, Post, Witte, et. al, 2008), usage and non-usage of electronic aids for people with tetraplegia (Verdonck, Chard, & Nolan, 2011), the quality of life of those who experienced high spinal cord injuries and lived in the community (Hammell, 2004), and the quality of life among persons on long term mechanical ventilation in comparison with those who do not use long term mechanical ventilation (Hammell, 2004). However, very little research has been done to examine the life experiences of this population. Examples of current research include how an individual woman with a spinal cord injury experienced everyday life (Isaksson & Prellwitz, 2010), the influence of social support for women with spinal cord injuries (Isaksson & Hellman, 2012), and identifying demographic factors, health and disability factors, and quality of life in aging with a spinal cord injury (McColl et al., 2003). Additional research about the perspectives of persons with tetraplegia may be beneficial.

When a spinal cord injury occurs in childhood or adolescence, it can cause a dramatic change in physical or mental abilities. According to Zebracki, Anderson, Chlan, and Vogel (2010), in most cases of pediatric onset of spinal cord injuries, the incident "propels them back to a level of dependence on their parents, disrupting their normative trajectory of increasing their autonomy" (p.17).

The person is also removed from contexts and roles such as school, community, and work experiences that may have once defined the youth. Dreams may have also been shattered, creating an opportunity for rehabilitation therapists to help with a smooth transition into adulthood. The authors of this study looked at the outcomes of transitioning into adulthood, and found that specific topics should be addressed in therapy including education and employment, independent living, transportation, social development, psychological functioning, risk-taking behaviors, and general health. Other research related to pediatric onset of spinal cord injuries includes substance use in young adults (Hwang, Chlan, Vogel, & Zebracki, 2012), mental health and secondary complications in adults (January, Zebracki, Chlan, & Vogel, 2014), depression and anxiety in adolescents (Klaas, Kelly, Anderson, & Lawrence, 2014), and psychosocial issues (Anderson, 2003). While there have been many studies done on pediatric-onset of spinal cord injuries, none have taken an in-depth look at the life experiences of an individual.

Little research has been conducted in the area of a person with a spinal cord injury in their upper teen to young adult years, a time in the lifespan that is typically focused on transition to adulthood. According to Cronin and Mandich (2005) when a person reaches the age of 15 or 16 years old, they have obtained a driver’s license and are able to begin working for a pay check. When they are about 18 years old, they typically have completed high school, left home to be on their own, and begun working in the labor force or on post-secondary education. Once they are out of the home, they are able to make their own choices and are accountable for themselves and their actions. Cronin and Mandich (2005) also state that “theorists have long emphasized the importance of companionship and intimacy during the transition to adulthood” (p. 275). At this age, the typical person searches for a partner to spend his/her life with, whether it is marriage or spending time with someone else. Sexuality also emerges with adulthood, which may correspond with the companionship sought. Between the ages of 20 and 40 is a time for optimal physical and intellectual functioning and when many life changing decisions are made (Cronin & Mandich, 2005). Additional research about the transition into adulthood includes assessing the stability of independent living, employment, and life satisfaction to determine the factors of reaching stability (Anderson, Vogel, Willis, & Betz, 2006), finding outcomes of adults who experienced pediatric onset of a spinal cord injury and his/her transition into adulthood (Zebracki, Anderson, Chlan, & Vogel, 2010), and transitioning to educational or career goals after high school (Heckhausen, Chang, Greenberger, & Chen, 2013).

Because of the medical complications related to a complete injury at C2, survival is less common. C1 – C4 injuries are typically ventilator dependent and the survival rates are not high compared to injuries in other areas of the spine. Doing a qualitative study on a young person who has all of these qualities (pediatric onset, C1-C4 injury, ventilator dependent) will result in a greater understanding of the experiences that aid in transition to adulthood; knowledge that may help friends and family members, occupational therapists, healthcare providers, and others who experience similar injuries to better understand what might be expected.

Problem Statement

Little research has been done specifically focused on the life experiences of persons with C1-C4 tetraplegia. Likewise, although the transition to adulthood for those with spinal injury has had some attention in the literature, no studies were found that specifically examined the transitional experiences of a young adult with pediatric-onset tetraplegia.

Purpose Statement

The purpose of this narrative case study was to describe the life experiences of a young man with pediatric-onset tetraplegia during his upper teen and young adult years.

Research Questions

The grand research question was: How does a young man with pediatric-onset tetraplegia describe his life experiences during his upper teen and young adult years?

The sub-questions included:

- How does the individual describe his life experiences, especially milestones and transitions?
- What are the individual's family, social, and other supports?
- What barriers or challenges does the individual face?
- How does the individual cope?
- How does the individual describe his quality of life?
- In what ways does the individual interact with others?
- How does the individual go about completing his everyday activities?

Significance of the Study

The significance of understanding the life experiences of a young man with tetraplegia through his upper teen and younger adult years may help occupational therapists working with this unique population, to aid the client in learning how to transition, how to cope, and even help within a school-based setting. It may also allow parents who care for a young adult with tetraplegia to better understand how his/her child hopes to be treated and to know about the kinds of possibilities that exist with the right technology and support. Other healthcare providers may begin to understand his/her role in treating those with tetraplegia and not limit the patient to the label of his/her diagnosis. Persons who experience an injury resulting in tetraplegia may be able to relate to others' experiences and find that they may also be able to use similar techniques, shape their lives based on what they enjoy, and be introduced to new ideas of occupations. Lastly, the community implications for individuals with disabilities in general can give one the ability to advocate for his/herself in regard to accessibility, expectations of how to be treated, and achievements one may personally accomplish despite what others may think.

Definitions

<u>Adolescence</u> – "The high school years (between 12 and 18), which are associated with physical maturation and puberty…also a period of learning, experimentation, and experiences that affect individuals' choice of long term occupations and their physical and psychological well-being." (Vroman, 2010)

American Spinal Cord Injury Association (ASIA) – An organization engaged in advocacy, education and research related to spinal cord injuries. This group produced an evaluation called the Standard Neurological Classification of Spinal Cord Injury that measures the level of motor and sensory capabilities of a person in order to provide the professional with information about how the injury affects them in regard to their motor abilities and sensation. (ASIA, 2013)

National Spinal Cord Injury Statistical Center (NSCISC) – This organization "supports and directs the collection, management and analysis of the world's largest and longest spinal cord injury research database". (NSCISC, 2013)

Paraplegia – "Loss or impairment in motor and/or sensory function in the thoracic, lumbar, or sacral segments or the cord resulting in impairments in the trunk, legs, and pelvic organs and sparing of the arms" (Radomski & Trombly Latham, 2008, p.1172)

Pediatric Onset of Spinal Cord Injury– "Spinal cord injuries that occur in childhood or adolescence produce a sudden or dramatic change in the physical abilities and functioning of youths." (Zebracki, Anderson, Chlan, & Vogel, 2010, p. 17)

Spinal Cord Injury (SCI): "The occurrence of an acute traumatic lesion of neural elements in the spinal canal, resulting in temporary or permanent sensory and/or motor deficit." (NSCISC, 2013)

Tetraplegia – "Loss or impairment in motor and/or sensory function in the cervical segments of the spinal cord resulting in functional impairment in the arms, trunk, legs, and pelvic organs" (Radomski & Trombly Latham, 2008, p.1172)

Transition – These years are characterized by dramatic life changes including personal, financial, and social changes requiring problem-solving skills and decision making abilities influences by life experiences, and major life decisions are made. (Wheeler & Shaw, 2005)

Role of the Researcher

Due to the researcher's background as an occupational therapy student, she began this research with some knowledge of the life experiences of individuals with spinal cord injury. For example, she understood the basic levels of injury, the prognosis, symptoms, associated conditions, treatment, and what functional outcomes are expected at each level of spinal cord injury. Additionally, the participant in this study was already known to the researcher. The researcher and the participant grew up in the same town and attended the same high school. They had classes together, were in extracurricular activities together, spent time together outside of school, and have a level of comfort and familiarity with one another. Because of this, she has some knowledge of the participant's life experiences, supports, and barriers, and some expectations of information. For example, the researcher expects to hear that the participant's family is very involved and helpful. Another expectation is that the participant may blame someone else for the accident in which he was injured. To mitigate these potential biases, the researcher engaged in ongoing reflexivity (Creswell, 2013), including journaling and writing memos throughout the development of the study, data collection, and data analysis.

While the researcher expected to be comfortable during the interviews with the participant, her goal was to separate her role as a researcher from her role as his friend. This role conflict may have influenced the way the questions were asked and answered. In order to aid role separation, the researcher began each interview by explaining the role change and what to expect during the interview. The participant also had the option to opt out of the study at any time, or could choose to not disclose certain information.

Limitations

This is a case study involving only one participant and does not reflect all individuals who have similar injuries. The researcher and participant's relationship prior to the study may positively or negatively influence the interview. Either the participant will be comfortable and open talking about sensitive issues, or he will feel uncomfortable and not want to discuss the topic with full disclosure. In order to mitigate these concerns, the researcher had an advisor involved for each step of the creation and completion of the study.

Summary

In summary, there is limited current qualitative research on people with pediatric onset of upper level SCIs. Because of this, more research is needed in order to understand the experiences and emotions that are congruent with the injury. The following chapter will review the existing research and stress the need for current information on this unique population.

Chapter 2

Literature Review

Introduction

This chapter will provide information about the functional outcomes of spinal cord injury, and a brief overview of the existing research related to coping with spinal cord injury, caregivers and other supportive resources, quality of life, independence, transition, and pediatric-onset spinal cord injury. Finally, the role of an occupational therapist with spinal cord injury will be discussed.

Functional Outcomes of Spinal Cord Injuries

Upper level spinal cord injuries create decreased independence for those who experience them. The higher the injury occurs, the more debilitating the effects. Specifically:

- C1-C2: results in the loss of breathing, requires the use of mechanical ventilation.
- C3: results in loss of diaphragm function, requires the use of mechanical ventilation.
- C4: results in significant loss of function at the biceps and shoulders.
- C5: results in potential loss of function at the shoulders and biceps, and complete loss of function at the wrists and hands.
- C6: results in limited wrist control, and complete loss of hand function.
- C7- T1: results in lack of dexterity in the hands and fingers, but allows for limited use of arms. (Radomski & Trombly Latham, 2008)

The level of injury impacts the occupations that the person engages in, and the amount of assistance they will require. According to Radomski and Trombly Latham (2008), persons with high tetraplegia (C1-C4), require external support for breathing, though most persons with C4 are able to build diaphragm strength and are able to breathe independently. Those who must continue to use a ventilator will receive their oxygen through a tube that is attached at the trachea. Levels C1-C4 injuries, both complete and incomplete, affect muscles, nerves, and organs from the neck down and require an increased amount of medical and caregiver attention. This may include removing secretions from the trachea, manually operating as a ventilator, and understanding how to operate the mechanical ventilator. This population may learn to direct their own care, select appropriate equipment needed for life support or daily functioning, and learn to use a mouth stick to enable them to turn pages, draw, type, paint, and play board games (Radomski and Trombly Latham, 2008).

Coping with Spinal Cord Injury

A study on major depressive disorder one and five years after spinal cord injury was conducted to estimate changes in depression. This study gathered information to identify demographics, injury, and discharge factors associated with major depressive disorder as well as modifiers that change the outcomes. Participants who had a follow-up one year post injury between the years of 1975 and 2010 were retrospectively viewed. Inclusion criteria included inpatient care, treated within one year of injury, have a degree of neurologic impairment following a traumatic event, gave consent, and reside in the geographical area of the study. Of the 2,830 selected from the database, 2,256 participants were analyzed. The researchers used the Patient Health Questionnaire-9 to determine the disorder. Results showed that the percentage of prevalence of the disorder was higher one year post injury as opposed to 5 years. Prevalence was also higher in those between the ages of 35-55 years old at injury, those who were unemployed or had a high school education or less, had a catheter, and had higher scores on the ASIA assessment (Arango-Lasprilla, Ketchum, Starkweather, Nicholls, & Wilk, 2011).

Another study explored patients' ability to cope with spinal cord injuries. Eighteen participants were recruited from two different centers in Iran, and their experiences were analyzed. Within this qualitative study, these themes emerged: "knowledge," "financial resources," "employment opportunities," "suitable facilities and accessibility," and "societal acceptance and support," which were all identified as barriers, and "self-confidence," "religious beliefs," "support networks," and "positive thinking" which were all coping factors. The results show that insufficient information was provided for the patients and many of them were required to learn how to cope on their own. A lack of accessibility and training centers were two examples of barriers for these patients. Having confidence in themselves, their religion, and family support were found to be the best coping mechanisms for these patients (Babamohamadi, Negarandeh, & Dehghan-Nayeri, 2011).

A narrative approach was taken by Isaksson and Prellwitz (2010) as they interviewed one woman about her life after her spinal cord injury. They interviewed her three times using open ended questions. Through the interviews, they focused on her everyday life and how she learned to cope with her injury through her experiences. This narrative used different themes to piece together her story for the study, which included “A Changed Life Situation,” “Mixed Feelings,” “A New Insight,” and “A New Road.” The researchers collected and transcribed her interviews, following it with their own interpretations. They concluded that her rehabilitators were not being client centered, adding negativity to her emotions instead of helping. These authors also found that using qualitative inquiry can provide more knowledge about a client by creating a picture of their whole being. This approach can be useful to healthcare providers in treatment planning as well as helping the client feel more comfortable and helping to improve the client's relationship with each other as well as his/her family members.

Caregivers and Support

A study on spinal cord injuries looks at the effects of peer mentoring to increase self-efficacy and decrease health complications. The purpose of this study was to explore the benefits of using peer mentoring to cope with a spinal cord injury. These mentors were able to help with information and education as well as community reintegration. Twenty-four people completed the mentoring program and results show that 67% had an increase in self-efficacy scores between the beginning and the end. Medical complications also decreased in that time period (Ljungberg, Kroll, Libin, & Gordon, 2011).

Another study was conducted with the husbands of women who experienced spinal cord injuries. The purpose of this study was to understand the experiences of the men and the social supports inside their relationships and outside. Researchers were also able to ask the men about the changes they went through and create a narrative form of analysis. The four men who were interviewed needed emotional and practical support, of which the amount changed over time. They also found that health professionals were able to provide the men with strategies that helped them cope with their sudden life change. (Isaksson, Josephsson, Lexell, & Skär, 2008).

One study was conducted with eleven different women, each with a different level of spinal cord injury. The goal of the study was to describe how social support influenced rehabilitation. The stories were narrated and analyzed by occupational therapists whom specialized in that area. The occupational therapists grouped the stories into five separate themes based on commonalities in the women's stories; discovering the importance of social networks to encourage the women and influence health and well-being (Isaksson & Hellman, 2012).

Another study looked at the quality of life and experiences with caregiving among persons on long term mechanical ventilation in comparison with those who do not use long term mechanical ventilation. The participants were between the ages of 26 and 77 years old, with 67% being male. Ten individuals were on long term ventilation as a result of SCI, eleven used long term ventilation as a result of other etiologies, and twenty-two individuals were the comparison group who were one year post spinal cord injury. All of the participants with SCI had to be in the A and B levels of ASIA with tetraplegia, one year post injury, sixteen years or older, history of SCI, and use or non-use of long term ventilators. When looking at the quality of life, it was considered in three ways for the study: health related quality of life, global cognitive appraisal, and individualized/judgmental. The researchers examined the differences in the quality of life and the quality of caregiving and found that no significant difference was apparent with quality of life. However, there were differences in caregiving, which was associated with cognitively appraised quality of life (Hammell, 2004).

Quality of Life

Another study looked at the demographic factors, health and disability factors, and quality of life in aging with a spinal cord injury. The participants were 352 American, British, and Canadian, and were extracted from member databases, spinal cord injury centers, and hospitals. The participants were included because the injury was 20 years prior to the study, they had been admitted within one year of injury, and were between the ages of 15 and 55 at the time of injury. The participants were given a combination of self-completed questionnaires and interviews; the other data included demographics, injury-related variables, health factors, quality of life, and aging perceptions. The researchers found that quality of life was affected directly and indirectly by age, health and disability problems, and perceptions of aging. The study found that people who have fewer problems related to disability are more likely to report a disadvantage in aging while the younger participants reported fatigue (McColl, et al., 2003).

One study explored the quality of life of those who experienced high spinal cord injuries and lived in the community as well identifying factors they identified as barriers or facilitators to quality of life. The participants were men and women with injuries between C1 and C4 who lived in urban communities in Canada. They were interviewed and themes emerged from the data analysis: participants' experienced their injury between 4 and 28 years prior to the study and the average age was 35 years (range of 21 to 50 years old). The participants explained that plans, daily activities, and occupations were disrupted due to injury, and that they initially felt helpless and useless. At the time of the study, all of the participants agreed that they were happy to be alive and some of them stated that they had a high quality of life. Throughout the years after the initial injury, the participants recounted how they had to refocus and reestablish self-views of being valuable. Themes that emerged include "autonomy," "the meaningful use of time," and "relationships". This study concluded that life with a cervical SCI can be rich and fulfilling if supported by society and that the quality of life outcomes could be optimal if a biographical orientation is adopted by the rehabilitation process (Hammell, 2004).

Independence

A study focused on autonomy in upper level spinal cord injuries, though the focus was specifically on participants with level C6 and C7 injuries who were members or past members of a rugby team. This qualitative study focused on the different strategies the players used to achieve independence (Van de Ven, Post, Witte, et. al, 2008). Strategies for autonomy included self-determination, participation, and self-identification. Data was retrieved through interview as well as a previous literature review. The participants were both male and female and were between the ages of 27 and 55 years of age. Throughout this study, the authors realized that different levels of autonomy require different strategies and it is unique for each person.

Researchers in Ireland compared the usage and non-usage of electronic aids for people with spinal cord injuries between levels C3 and C5 (Verdonck, Chard, & Nolan, 2011). A qualitative approach was taken with this study with interviews being the main data source. Data between users and non-users were grouped together and it was found that electronic aids did in fact increase autonomy. Two themes found were “Time Alone,” and “Changed Relationships”. By having electronic aids, independence should improve. Electronic aids include: remote controls, telephones, door controllers, and much more. Reasons that non-users did not have equipment had to do with limited resources and costs to obtain the items.

Transition and Spinal Cord Injury

Transitioning from adolescence to adulthood with a disability is a well-researched area. In understanding the process and outcome of patient focused goal planning, one hundred newly injured patients with spinal cord injuries were given the Needs Assessment Checklist, a goal planning questionnaire, and a goal planning progress form. Quantitative results on physical, social, and psychological functioning revealed that patients improve significantly from the beginning to the time of discharge. When conducting the qualitative analysis, it was found that benefits were reported in those same three areas (Byrnes et al., 2012). Patient focused planning has shown significant changes in the rehabilitation experiences of those with spinal cord injuries.

One study assessed the stability of independent living, employment, and life satisfaction to determine the factors of reaching stability. One hundred sixty-six participants who had sustained their injury at eighteen years or younger and were twenty-four years of older at their first interview, were interviewed three times annually. Measurements included: the Function Independence Measure, the Craig Handicap Assessment and Recording Technique, the measure of perceived health, and the Satisfaction with Life Scale. The average age at the time of the interview was 29 years and of the one hundred sixty-six participants, 64% lived independently at the first interview, and 90% of those continued to live independently. 64% were employed at the first interview and 83% continued to be employed at later interviews. In terms of life satisfaction 48% reported they were satisfied and 84% continued to be satisfied at later interviews. The researchers found that some of the factors for stability included physical independence, mobility, and occupation, sex, race, independent living, and cognitive independence. Satisfaction factors included occupation subscale and fewer pressure ulcers. The study concluded that those who experienced SCI at 18 years old or younger can achieve stable adult outcomes, providing information that helps to improve rehabilitation for future patients (Anderson, Vogel, Willis, & Betz, 2006).

A general longitudinal study on transitioning to educational or career goals after high school looks at whether or not it is beneficial to consider the year after high school or two-four years out of high school. Over 1,000 typical high school seniors in Los Angeles were a part of this study, and were followed for four years after graduation. The researchers found that students who indicated motivational engagement goals after high school predicted attainment and psychological well-being at two and four years after graduation, with occupational progress at four years following leaving high school. Work hours assessed after graduation were associated with poorer educational and occupational outcomes both two and four years out of high school. They concluded that having educational goals created better outcomes compared to those who had career oriented goals directly out of high school. Having educational goals is an important component of successfully transitioning into adulthood (Heckhausen, Chang, Greenberger, & Chen, 2013).

Pediatric Onset of Spinal Cord Injury

A study was done on the outcomes of adults who experienced pediatric onset of a spinal cord injury and the transition into adulthood. Though many of the adults were able to independently complete activities of daily living, living independently was lower than expected. In order to live independently, one needs to consider the factors of being physically independent, being an active participant in the community, being employed, and being satisfied with life should all be taken into consideration. The study found that in a survey of sixteen to twenty-one year olds with SCI, 52% drove independently, while between the ages of twenty-four and twenty-five with a pediatric onset, it increased to 62%. They also found that emotional support through family, friends, and significant others was linked to overall life satisfaction. Family also played a role in positive development, and rates for being married were between 46% for men and 58% for women. Some adults took on the challenge of being social while others were likely to experience social isolation. Of those who were social, a longitudinal study showed results of pediatric-onset of SCI dating at approximately 44%, married at 21% and being physically intimate over the past year at 64%. This study also found that it was important to work on transitioning to help prevent other SCI complications since those with pediatric onset are at risk for complications for a longer amount of time. This approach to transitioning should be flexible, unique to the individual, promote independence, and encourage decision making for the individual with SCI. For a successful transition, healthcare providers should also address medical, cognitive, emotional, and social concerns as a person with SCI will be challenged with many obstacles (Zebracki, Anderson, Chlan, & Vogel, 2010).

Another study looked at the connection between posttraumatic stress, family functioning, and the level of spinal cord injury to functional independence for those with pediatric onset of SCI. The ages of the 109 participants were between eleven and twenty-four years old. The researchers found that the level of SCI had a direct relationship to functional independence and posttraumatic stress created a connection between family functioning and functional independence. Using the Posttraumatic Diagnostic Scale, symptom clusters allowed groups to be identified based on reaction to stress. This scale in conjunction with this study yields results showing that avoidance creates a relationship between re-experiencing symptoms and functional independence as well as arousal and functional independence (Boyer, Nowcid, & Ware, 2012).

A cross-sectional study was conducted to understand the importance of religion and spiritual coping and the role it played on life satisfaction in adults who experienced pediatric onset SCI. The participants were eighteen or younger at the time of injury and between the ages of twenty-four and forty-five at the time of the telephone interview. A total of 298 participants took part in the study. Almost half reported religion was important while more than half reported using spiritual coping. One of the main differences between the two is the fact that spiritual coping appeared to be a predictor of satisfaction with life while religion did not. The researchers concluded that the assessment of spirituality needs should become a standard in treatment as well as a focus in intervention in order to promote life satisfaction (Chlan, Zebracki, & Vogel, 2011).

Role of Occupational Therapist

The role of the OT in treating spinal cord injuries consists of family education, adaptive equipment, and self-management. During the acute care of the client, the occupational therapist will be flexible with work hours, provide support during fatigue and pain, establish environmental controls, and maintain upper limb range of motion to prevent deformities (Radomski & Trombly Latham, 2008). During this time, the occupational therapist will also begin to educate the families and caregivers. Caregivers will need to know how to help with proper hygiene, dressing, feeding, and preventing further health issues. The therapist may provide some education through educational materials or videos (Radomski & Trombly Latham, 2008) or work alongside the families to provide a comfort level beginning in the acute setting and spanning across their lifespan.

Because the person with this type of injury has limited mobility, specific pieces of equipment may be used to provide increased autonomy. For example, a sip and puff wheel chair may allow someone with a cervical injury to become mobile from room to room. But depending on the individual’s capabilities, other wheelchairs can be utilized and will be utilized the patient's entire life (Radomski &Trombly Latham, 2008). The occupational therapist will also help the client and caregivers choose the appropriate chair for his/her individual case. Caregivers should be alerted to specific body reactions that may end up being a medical emergency if not properly addressed. An example of a life-threatening condition is autonomic dysreflexia. Autonomic dysreflexia is “a sudden dangerous increase in blood pressure, [it’s] a possibly life threatening complication associated with lesions at the T6 level or above” (Radomski & Trombly Latham, p. 1175, 2008). This may occur when their bladder is full, if there is a urinary tract infection, pressure ulcers, ingrown toenails, and other noxious stimuli. In order to prevent it, the occupational therapist should provide caregivers with the education needed to understand how to keep these things from happening and what to do in case of a symptom (Radomski & Trombly Latham, 2008).

Among other education, the occupational therapist will teach both the client and caregiver on how to prevent pressure ulcers by using pressure relief techniques. The client will also learn how to tell caregivers and others around them what they need and should be able to provide the education to those who are unaware of how to help. Nurses are the main educators when it comes to the bowel and bladder management, but occupational therapists will also help in this area, especially when it comes to assistive equipment that will aid with the task (Radomski & Trombly Latham, 2008).

Transitions are also a large part of the therapist's role. The therapist is present through acute care, inpatient, and outpatient settings. As the client prepares to return home, certain items should be discussed. Since rehabilitation programs are shorter than optimal to achieve client goals, it is important that outpatient therapy is utilized. Clients will learn new movements, how to perform activities of daily living, and reach goals that are set. The home environment will also be considered. Layouts, doorways, and stairs cannot be approached like before. The therapist and the families will discuss modifications before returning home, and will continue to be addressed after the return (Radomski & Trombly Latham, 2008). Emotions and expectations should also be discussed throughout the time after injury. The family should be aware of all the possibilities that may occur, be prepared for them, and understand that their experiences are normal.

All of these tasks can be intimidating if taken on alone, thus it is the role of the therapist to provide support in all of those areas.

Summary

Despite the present amount of research in the area of spinal cord injuries, there has yet to be a study completed on a young man with a C2 injury. This study could help friends and family members, healthcare providers, and other people who are experiencing similar injuries understand how someone else learned how to cope and continued to be resilient through the injury.

Chapter 3

Methods

This narrative case study describes the life experiences of a young man with tetraplegia during his upper teen and younger adult years. A narrative case study was selected because the study is biographical, included the experiences of one individual, stories and data were collected through multiple sources, and the researcher used the practice of re-story to convey his life experiences (Creswell, 2013). This study was approved by the University Institutional Review Board.

Participant Selection

The participant was purposefully selected based on meeting the inclusion criteria of being between the ages of eighteen and twenty-five, having tetraplegia between levels C1-C5, and living in Kentucky. The only exclusion criterion was being non-verbal. Gender was not relevant. The primary investigator was familiar with an individual who met the criteria and who agreed to participate in the research. The study was described to the participant and the researcher sought consent through a letter that was signed by a caregiver and the researcher (Appendix A). Additional consent was required due to the researcher knowing the participant in order to fully ensure voluntary participation (Appendix B). After being given options of auditory, electronic, and paper signature, the participant chose to have his mother, who is also his power of attorney, sign the documentation. One copy stayed with the participant and one copy stayed with the researcher. After consent was received, a time and location was determined for the interview to be conducted.

Data Collection Procedures

Data was obtained through two individual semi-structured interviews that lasted between 60 and 90 minutes. Prior to the interview, the participant received a copy of the interview questions (Appendix C) in order to contemplate questions that may be more difficult, prepare a response to prevent being caught off guard, and allow full consideration of each question. The interviews took place on the participant’s front porch, per the participant’s request, although privacy was not always possible in this setting. The interviews were halted during interruptions in order to preserve confidentiality. The interviews were conducted, recorded, and transcribed verbatim by the primary investigator. Data was also collected via direct observation of the participant during interviews at participant's house including objects in the environment, involvement in activities, and interactions with family members. The investigator took field notes describing the observations.

Data Analysis

To analyze the data, the researcher coded the verbatim transcription line by line using in vivo codes, which resulted in approximately 500 codes. These codes were then sorted and categorized into related topics, with duplicates removed. One category consisted of background and demographic information, and this was re-storied into a narrative that described the participant’s history and current circumstances. The remaining categories were analyzed until six themes emerged from the data.

Verification

In order to ensure trustworthiness, the researcher's advisor and committee members used peer review to provide an external check on the primary researcher's process. The researcher also presented the findings to classmates who provided positive feedback and critiques as a form of peer review. Member checking was attained by sending the participant the interpretations in order to achieve credibility and confirm the facts. Clarifying researcher bias from the beginning was another way the researcher accomplished accurate verification though journaling bias prior to the interview, checking the work to exclude these biases, and writing memos throughout the interview and the process (Creswell, 2013).

Summary

This study used narrative case study methods to describe the life experiences of a young man with tetraplegia during his upper teen and younger adult years. Data was collected via interview and observation. The data was analyzed line by line using in vivo codes. Verification methods were used for trustworthiness. The next chapter will discuss the results of the study.

Chapter Four

Results

This narrative case study had one participant, Joshua (pseudonym is used to protect anonymity). Below is a narrative description of Joshua using information and direct quotations from his interviews. The narrative was reviewed by Joshua for accuracy.

Narrative Description of Participant

Joshua is a twenty-four year old male who lives at home with his mother, step-father, older brother, and younger sister. When he was five years old, he was in a car accident that injured his spinal cord and left him paralyzed. Because his cervical spine was affected, he is identified as a young man with tetraplegia. His injury occurred at level C2 and as a result he is dependent on a ventilator. The doctors and other healthcare providers explained to his mother that he most likely wouldn't survive the injury, but if he did, he would be "a total vegetable".

Within his lifetime, he has been in the hospital numerous times including the initial accident as well as health complications like pneumonia, and had "lots of surgeries". Therapy was helpful but not always hopeful for Joshua. He received occupational therapy from the time of the accident until middle school and physical therapy until freshman year of high school. Joshua would go from the extreme of lying flat for a very long time and the only other position he experienced was being placed in a stander. He remembers hating the experience. The occupational therapist "did evaluations on some assistive tech but really the only piece to really impact me that much was the computer". They also tried to help Joshua feed himself, but “really they did not do a ton”. Other than that, he can’t remember anything memorable that the occupational therapist did with him and recalls finding most of his equipment on his own. The physical therapist on the other hand really focused on helping him gain head and neck control after the accident, enabling him to hold his own head up. The physical therapist also did a lot of the basics including “stretches, splints, basic equipment, chair, etc.” When asked if he would recommend therapies to others, he responded with “yes, I would but I would also recommend doing some of their own leg work because you learn a lot doing it… like doing their own research not relying on a therapist for every answer”.

Before Joshua’s accident he was a typical developing little boy. He played Little League and sold snow cones and lemonade at a stand. Since his father left when he was only a few months old, his grandfather assumed the role of father, spending time with little Joshua, forming strong bonds, and making a huge impression on him as he grew. As he was entering adolescence, his step-father became a part of his life, and years later his little sister entered the family.

Family has been a big part of his life. Joshua explains that his family has always been close, including the extended family. They tend to have get-togethers two to three times a month and about 40 people attend the event. This tight knit family is always supportive of one another, helping each other out in any way possible. According to Joshua, “[when you] marry into the family, you get it all”.

Nineteen years after the accident, he is proud to say he is a high school and college graduate as well as a business owner. Right out of high school he took advantage of “the first thing that came along,” which was purchasing an indoor soccer field. He had a good time with the soccer field and he learned a lot, but after several years he was ready to move on. He sold the company after realizing it wasn’t “something I want to do with the rest of my life". He explained that “it was one of those phases” and once he was done with it he was “ready to just try something new”. So Joshua went back to college where he earned his associate’s degree in business and started his own business upon graduation. He is currently working on building a company that will consult with persons with disabilities and for large venues and government buildings, providing resources and knowledge about accessibility. Once that business is up and running, he mentions that he will “more than likely go from business to business”.

Themes

After analyzing Joshua’s interviews, six themes emerged from the data: I *always have someone with me, I’m not easily broken, I’m stubborn, I’ve made it the best I can make it, I’m just like everybody else, Right now it’s about me doing what I want to do.* These themes are described below with verbatim quotes to provide support for the research questions.

I Always Have Someone with Me

Joshua always has someone with him because he needs someone to help him with daily tasks such as eating, using the restroom, caring for his equipment, engaging in leisure activities, getting dressed, and bathing. His states that his caregivers provide him with “anything I need” and do “pretty much anything I would need or want on a daily basis”. In Joshua’s words, “they are my hands and feet”. He “needs help with everything that most everybody takes for granted,” which means that his nurse, family members, or friends with knowledge of caretaking are always present to help him with his daily needs. If a nurse or caregiver weren’t present, “tubes on the ventilator could come loose” or “batteries could die.”

Since he only has nursing care for 16-20 hours in the day, his mother and brother are also trained to care for him. Additionally, he has at least one good friend who has observed his care since they were children, giving him the knowledge of how to care for Joshua. This friend has known Joshua for 19 years and is always there for him; doing anything he would need done on a regular basis. However, not all of Joshua’s friends are also caregivers. Overall, Joshua reports that he has a great group of friends who, though they may not assume the caregiver role, they still enjoy doing things for one another and spending time together. Only his mother, brother, and a handful of friends are able to assume the caregiver role in the absence of a nurse, allowing someone to be with him at all times.

Because he always has someone with him, it means that people know a lot about him. When asked if he puts forth a different façade in public than at home, he simply responded with, “people are gonna find out who you truly are anyways” and that “you might as well make ‘em mad for who you are instead of being somebody you’re not”. He also states that he thinks that “everybody is a little bit different than what they are on a day-to-day basis," and that when you are "around the people that are truly your friends, especially your family, it's hard to hide".

Joshua is never alone throughout his day, relying on nursing staff, family, or friends to help him with his medical needs as well as completing tasks throughout the day. He is an open book, whether by choice or necessity, but doesn't appear to mind the company.

I'm Not Easily Broken

According to Joshua, most people think he is fragile. His sister may be one of the first to tell you that he is not. His five year old sister jumps on the bed, rubs his head, and even jumps on top of him and holds his head in her arms as she dangles there. Joshua explains that "it doesn't hurt when she jumps on top of me," but that "people freak out when they see a five year old jump on top of me". In his experience with others, he finds that "some people are afraid to grab me and give me a hug," and that most are "afraid of invading his personal space". His personal space has in fact "been invaded since I was five" and it "doesn't bother him at all" because "I don't have any shields".

Not only is Joshua physically capable, he is emotionally strong. When he gets angry, he tends to "just let it bottle up so when I does blow up, I blow up, and it ain't good". He explained that "there's quite a few choice words normally," and that "sometimes it's probably best that I'm in the position I'm is in so I don't kill somebody," because "when I explodes, I explode". And because he is always with someone, he discussed those emotions by saying "if you're around somebody enough, you always get upset/frustrated/mad… you just need space for a while". Just like most people, he says that "when you deal with people enough, you end up getting mad". And he handles being mad by talking to his friends because "that's always a good way to let out frustration… talking to people is the best therapy". He has "some friends that I talk about the other group of friends and vice versa".

Whether it's business or just going throughout his regular day with family and friends, "I'm pretty blunt with people". His whole family has a similar trait of "pretty much always say what we want". It may be considered "communication or being loud and outspoken," but it's common among the family. And when Joshua is "angry, nine times out of ten, people know it," but "people know if I'm excited too".

I'm Stubborn

Joshua's mother "always raised me the same as my brother," and he says he "has to thank her for that". She raised him "to be stubborn". He explains that "she's stubborn and so am I". And based on the way his mother raised him, he explains that "I've always been stubborn since I was real little".

Due to his stubbornness the quote "prove people wrong" came up quite often. People would tell him one thing, like that he is "crazy for my ideas" or that he may be extreme, but he has his heart set on proving people wrong. Despite assumptions of most people, and despite other people's expectations for him, he explains that "if I want to do something that somebody told me that I couldn't do, or they say it's a challenge, I learn real quick how to think outside of the box to come up with a solution," proving just how stubborn he can be when challenged. He mentioned that "people assume disabled don't work," and has again exceeded their expectations by going one step further and owning his own business.

Joshua believes that being stubborn is a good thing. He explains that "being stubborn affects me positively… [because it] gives me drive and determination". He also states that "stubbornness is always good for business," because his best three qualities for running a business include his "business knowledge, creativity, and stubbornness". And based off his knowledge, he knows that "a million other companies wouldn't be around today if they took no for an answer".

He and his family pride themselves with being stubborn. Being able to survive and accomplish goals throughout life wouldn't be possible for Joshua without having this quality. Proving people wrong and having drive and determination through this quality have helped him get to a point in his life where he is able to be proud.

I've Made It the Best I Can Make It

In the words of Joshua, "I believe with what I've been dealt, I've made it the best I can make it, and strive to make it better each additional day". In regards to faith, he states that it has helped him and that "without Him, I don't believe I would be here today". He also believes that "I shouldn't be here today, for more than once in my life… [but] I'm here so I must be here for a reason…who knows what that reason is except God". With his injury and life following he explains that “you just kinda gotta take it and deal with it…but then you sit back and think you were dealt this hand for a reason”.

He says “there’s always a wish that I could walk,” but he understands how there must be some greater reason he is here. He has learned a lot about life, “especially in my situation,” and explains that he’s “lazy by necessity, not because I choose to be”.

From being in his situation, he is able to experience life through a different paradigm than most people. In his words, “I guess we’re still considered the minority,” when it comes to being disabled and accessing venues and buildings. He has formed his business based on his experiences in venues and other buildings. When he was at concerts or sporting events, he found that there were constant issues when it came to handicapped seating. Common issues include “limited view,” “seems like they didn’t consider it,” “their employees aren’t informed,” or “they don’t know how to fix the issue”. He found that “during the game I wouldn’t be able to see,” and that some venues were “willing to fix it and others are just sorry about your luck”. And again, some of these venues “have good policies in place or are more accessible than others,” but the biggest issue is if “ticketing services [are] selling the correct seats. Even though “Ticket Master says they sell you accessible seats,” they are not, or “they [may] change the seating arrangements”. When he complains, “the fire marshal gets a lot of the blame,” because employees claim that “this is where the fire marshal said our accessible seats had to be”. People stand up and cheer during games and concerts, and may continue standing, which makes it hard to sit behind them and still be able to see what’s going on. Joshua plans on using this experience to build his business to enhance other disabled people’s experiences in these venues as well.

In order to make the best of life and to be satisfied, Joshua tries to be a good person in many ways. He’s pretty satisfied in general and says that “it doesn’t take much to satisfy me,” and that he bases it on how he feels and how he makes other people feel. Basically, “if you’re happy with life, you’re satisfied”. Much of his satisfaction comes from being able to “help people out in life”. Within his venue experience and the creation of his business, his goal is “helping people that have a disability or in the situation where they need something that I can help point the way”. His business consists of “consulting for people with assistive technology,” and being a “resource for people’s needs”. And when it comes to his friends he says that love is “just doing something that people don’t normally think of, you know, just to bring them out of their slump or whatever it is”.

He finds his fulfillment “partially within… [and] partially with the people I’m surrounded by”. And he says that it’s not necessarily about making the world a better place, but striving to do better and not living off the government. In his words, “I think you can die and say you lived a fulfilled life if you know you’ve tried your darndest to make the best that you can make it”. Joshua would love to help others in many ways and hopes that “I’ll impact somebody’s life somewhere along the line”.

Having a successful business is one of his goals, but he does not define how “most people measure success, like fortune 500 or whatever”. He doesn’t even consider how “success is measured by profit, the amount of customers and things along those lines”. Success is “a multidimensional word” to Joshua and he defines it as “measured by either self-gratification whether you are happy doing what you’re doing”.

In order to make the best of his life, he claims that “it all boils down to creativity”. Since he has such good friends and such a large network, he seems to have a “guy” for everything. In the case of being creative he’s “got these two guys [who will] find a way to make something work if they want it bad enough”. Between Joshua’s ideas, his research, and his connections, they can “come up with a solution for anything". He even has a couple friends that he refers to as “backyard engineers”. Joshua likes to think outside the box and is sure that “there’s a solution somewhere if you can just look and find it”.

In Joshua’s words, “The cornerstone of my business is to be able to get outside of the normal parameters of what people say should be done and think of a different solution of what could be done to reach a goal”. Ever since he was little, he has been a money-minded entrepreneur with plenty of ideas floating around. His current business is “something I kind of came up with,” based on his experiences, and “part of that has come from my situation”. He has been able to use his experience and creativity to craft something that is important to him and can help others make the best of their situation too.

Part of what he has learned over the years is that “life is always the best teacher because no matter how many textbooks you read, you never get the full grasp of what it really takes”. He attributes part of his success to “surrounding myself with people that know more than me on a certain topic”. And based on that advice, he has learned that “the cornerstone of being a good leader is being able to say you don’t have an answer, but finding somebody that does”.

The biggest part of his ability to make the best of life can be attributed to his mother. Joshua stated that “my mother’s been taking care of me for nineteen years and that’s the epitome of love”. He also understands that “there’s not a lot of parents that would dedicate their lives to something like that... I know it’s a big job”. When he discusses his sister, he alludes to how well she understands him, apart from his mother and his brother. He believes that for his sister to have an older brother in a wheel chair who is tetraplegia “teaches her to be accepting of others… and that it’s good for children her age”.

I’m Just Like Everybody Else

In so many ways, Joshua explains how he is just like everybody else. Things have always been “normal” to him because “ever since the injury, that’s [just] the way it was”. When it comes to life in general, he explains that “there’s nothin’ that I don’t think anybody else goes through on a day-to-day basis…and everybody has ‘down days’… it’s part of life”.

And though most people don’t realize it, he has the same feeling and urges as everyone else as well. His ability to have sex is “one of the biggest shocks that I get out of people”. Joshua states that he currently “chooses not to have a relationship just because I’m busy doing my own thing”. In the past he has been in relationships, but it was “typical puppy love…nothin’ serious”.

Though he wants to have a wife and children in the future, he's just "busy in life right now".

He is able to "get anywhere that anybody else can," "go to concerts, movies, fishing, and hunting," and go out to eat and drink with friends, which may include an alcoholic beverage. When his friends call and say "hey, do you wanna go, I say okay, let's go". He thinks "that's the same with everybody". He enjoys music, sports, fishing, and hunting, making a point to be very involved when possible. He also doesn't feel like he's missing out on anything and in his own words says, "It ain't like you're missing out on anything that is anything different".

Joshua's love of music is evident when he speaks of music. He has loved music as for as long as he can recall and believes that his grandmother may be one of his influences early on. He says she was always singing and was very musical. Joshua also brings up the fact that "music is pumped into our lives so much whether you're at a store or a restaurant or driving down the road…we always had the radio on here and there". Joshua goes to many concerts, trying to average about one concert a week, and could go to as many as three in one week. He listens to a variety of artists and has had the opportunity to meet 75-100 famous people in the music business. When asked how many famous people he has met in general, he acted modest mentioning that he has "met a couple actors here and there", and the number continued to sky rocket.

During his journeys to concerts, he may be in a vehicle with someone for five to six hours at a time and claims that "it's more than just a concert". Since some of the concerts are so far away, “I’m always travelling somewhere [and find that] you learn a lot about people when you go on a road trip… good or bad it’s always fun”. His tastes and emotions with music are similar to most people; he “can listen to music at all times… [but it is] dependent on what mindset I’m in at the moment”. When he finds a band he really likes, he branches off from that artist of genre, getting deeper into his music of preference.

Joshua has season tickets to baseball and football games and also enjoys watching basketball. He considers himself to be a big sports enthusiast and views it as a hobby. He and a friend usually join two fantasy leagues each year, and even though “I’m not the best at it… it’s always fun to do”. Joshua appears to be the odd man out with his love of sports because “none of the family was really into it,” but he has just always liked and watched it.

Joshua and his friends can “just go fishing wherever we want to go fishing”. Though there is some assistive technology available, the main piece of equipment he uses is the item that is “more designed for guys that are fishing with more than one pole”. This device holds the pole while after the fisherman has cast out. In Joshua’s case, his buddy baits, casts out, and reels in the line. Joshua is the “eyes on the pole,” making the fishing process “a joint effort”. He rides in the passenger’s side of his truck, that he was able to modify to fit his needs, to get to their destination. Then “I’ll watch a line or two while my buddy watches a line or two” and he says “the rest is pretty much standard to anybody else going fishing”. There is more available technology to help disabled fishermen “become more independent for casting and reeling,” but it is “nowhere as advanced as the gun devices”.

He was taught about guns at a very young age because his uncle was a police officer. Joshua remembers how “he always had his gun here and there and we were taught to not touch it”. His uncle would “teach us anything we needed to know about guns”. Joshua is currently looking into assistive technology for guns that “enable[s] people with limited movement the ability to hunt”. He also owns quite a few guns, but doesn’t like to call it a collection because “collections are not meant to be used,” but his guns are. His friend normally does the shooting and because Joshua lives on a farm, “hunting is a little bit easier,” because they have the “luxury of sitting on the back porch until we see a deer”. He explains that his hunting is “normal like anybody else”.

Like most people, Joshua keeps in contact with people from the past, sometimes through Facebook and Twitter. He has friends that he graduated with, friends that visit him, and a specific friend that brings him brownies that are “the definition of love”. He makes sure to tell his friends that he loves them because “people need to know when you love ‘em, you love ‘em,” and that “it’s not said enough”. He also has several platonic girlfriends that he will send flowers to if they are having a bad day, just to “bring them out of their slump.

Joshua also has “everybody’s typical goals, I think”. He wants to get married and have a family, maybe two kids because he wants his children to “have a similar relationship to mine and my brother’s”. In the future “I’ll be looking for a girl to become a wife," but "right now there's no girlfriend or wife, or any plans to be one for a while".

He speaks of his sister fondly, stating that "she keeps it interesting and fun". She occasionally asks about the chair and knows they had a car wreck years ago, but he guesses that "at five, that satisfied her curiosity". Like most older brothers, he gets annoyed by his little sister, but will let her "watch her cartoons when I'm wanting to watch a ball game… letting my little sister invade his T.V." And as most older siblings are influential, "she's now got to the point she'll watch the ball games with me".

Joshua and his older brother are also very close. He says "We can kill each other. We would kill for each other." Sometimes his brother makes him mad, which brothers are notorious for, and "just like a normal brother would… I'll call him an [expletive]". He and his brother have a lot of time to bond when they go to concerts together and when asked about their intimate moments, he said that "my brother's thought of intimacy would be punching me". And despite the way they pick on each other, Joshua considers him "good psychological help".

His little sister does not view him differently and she gives him hugs all the time. Others tend to hug him when they greet or leave him. And though some people are afraid to encroach on his personal bubble, others do not seem to care because they know him and the fact that he doesn't really have personal space to call his own, nor does he mind.

Right Now It's About Me Doing What I Want To Do

Joshua recently bought a new truck that he had modified to fit his needs. The truck's passenger side slides out and down, picks him up, and places him into the front passenger's side of the vehicle. It was "the first time in nineteen years that I was able to ride in front of a vehicle… and the first time I had been to the back of [our 100 acre] property". He wanted this truck because he was not only able to sit in the front, but because he wanted to "go back on the farm and go fishing'".

In regards to assistive technology in his home, he picks and chooses what he wants and deciphers what he needs. There is a company that he works through that seems to offer "a million possibilities" including phone calls from the computer, raising and lowering blind, opening the front door, locking and unlocking the front door, etc. But there are at least two reasons Joshua chooses to not have some of the technology available; "technology is expensive," and somebody is there to raise and lower his blinds. He states that "some of the assistive technology is fine and I need," others I doesn't use that much…you normally raise and lower the blinds once a day". So he could have the means to control just about anything in his home, but chooses to not take advantage of it at this point.

Once Joshua is in his wheelchair, he is able to move independently and go "wherever I want to go". He uses some assistive technology to "independently control the T.V., lights, and the computer". Though Joshua needs help with most tasks, he is able to do these few things independently. He takes advantage of his ability to be mobile in a chair, getting himself from one place to the next. He also takes advantage of being able to independently control the T.V. to watch sports or occasionally share the television with his little sister to watch cartoons.

When Joshua switched schools in high school, he found that though his first school was more adaptive, his new school was still very accommodating. The principal was excellent at making sure he had everything he needed, though most needs were basic. For example, he “needed a music stand to set my books on,” but he “brought all my computer equipment with me”. The school was small, having only one hallway for the high school, so “accessibility was pretty easy”. As for having constant care, “they hired a nurse to go to school with me,” and the only thing they really did differently was “[leave] class a couple minutes early so the hallway wouldn’t get too crowded”.

Right out of high school, he decided he would own his own business, and in terms of accessibility or major changes in the transitioning, it “wasn’t extremely different”. He points out that “everything was on one floor… [the] doorways were wide… [they] really didn’t have to adapt anything for me to get around… [maybe] move a couple pieces of furniture”. Joshua explained, “I wasn’t doing a lot of the paperwork or anything like that, I had somebody do that”.

When Joshua decided to go back to college, he found that more adaptations or accommodations had to be made for the transition. At first he mentioned that his “same nurse went with [him] and it was good… [it made it] an easy transition because you’re used to working with somebody you know”. When moving around on campus, he says, “you learn short cuts…which buildings to cut through”. He “used the chair to get around campus… [and] parking was really bad…whether a professor or anybody else”. The distance was another big change for him once he reached college because “classes were spaced out pretty far… [and] it wasn’t like you could get in a vehicle and drive to the other side of campus”. He had to plan around the distance because he “had to work [his] schedule out where everything was spread out to allow ample amount of time to get from point A to point B”. When Joshua was in high school “they let my nurse transcribe all my answers to the test… [in] college they want a teacher to do that or somebody from academic purity reasons”. He explains that “they had to provide certain things and do things a certain way… [and] finding help was fine as long as we could find one person to do it on a regular basis…[it] made it easier so you were working with the same person and you didn’t have to relearn how to work with somebody else”. Sometimes there was difficulty finding help, “math classes were probably the most difficult and mostly the teachers help with that because it’s kind of like speaking a foreign language”.

When asked about the biggest change from high school to now, he said that “instead of being scheduled, you have to schedule yourself… [in high school there’s a] five day a week schedule that’s basic for everybody”. He is thankful that even now he has the “same people helping me out every day”. He also says that “every once in a while [going back to college] seems like a good idea… [but] looking back at the schedule of college and the demand…I don’t think I want to”.

Throughout the entire interview, Joshua would throw in the phrase "just like anyone else," nonchalantly. He wanted to make sure that the research and the readers knew that even though he was in a chair and always needed someone to help him complete tasks, he could still find a way to do anything that any other typical human being does on a daily basis.

Summary

From analyzing Joshua's interviews, these six themes emerged: I a*lways have someone with me, I'm not easily broken, I'm stubborn, I've made it the best I can make it, I'm just like everybody else, Right now it's about me doing what I want to do.* Each theme was described using participant quotations. The next chapter will discuss the importance of these themes, what it means, the impact on the community, and future research.

Chapter 5

Discussion

The purpose of this narrative case study was to explore how a young man with pediatric-onset tetraplegia described his life experiences during his upper teen and young adult years. In particular, the study sought to understand the participant's experience of significant milestones and transitions as they related to his family, social, and other supports and/or barriers, his coping mechanisms, his quality of life, and his functional abilities. The themes that emerged from observing and interviewing Joshua provide a rare glimpse into the perspective of a young man with pediatric-onset tetraplegia. The perspective may be unique to this individual, but may also provide clinicians, caregivers, and others valuable information when interacting with a person with similar characteristics.

Although Joshua frequently mentioned that he was no different than anyone else, it seemed that many of his experiences separated him from the general population. For example, most individuals do not have a caregiver with them at all times. Joshua was able to engage in most typical activities, but he had to be creative and accomplish participation in unexpected ways. For example, when Joshua wanted to go fishing, he bought a truck and had it modified to meet his physical needs, allowing him to sit in the front passenger seat while a driven by a caregiver. In a study by Hammell (2004), the participants explained that plans, daily activities, and occupations were disrupted because of their spinal cord injury, but Joshua did not comment on any disruptions. Instead, he sought out creative, personal solutions. It may be possible that because his accident occurred when he was five, he was unable to compare his life with a previous iteration, creating the impression of not being different from other people.

Although Joshua noted that he required continuous support and care, he was still able to maintain a high level of autonomy and relative independence in his life. Joshua had a plethora of medical and social support from nurses, family, and even some friends who were able to assume the role of assistant, providing him the means to maintain a level of independence despite his high need for continuous care. Other studies have shown a similar link between caregiver support and autonomy in those with spinal cord injuries. A study by Ljungberg, Kroll, Libin, and Gordon (2011) showed an increase in self-efficacy and a decrease in medical complications in persons with spinal cord injury who worked with peer mentors. Another study showed the importance of social networking among women with spinal cord injury (Isaksson & Hellman, 2012). Joshua's support system, many who had been with him daily since the age of five, has proved to be good for his mental and physical health.

Joshua noted that his own internal characteristics were essential to his experience of autonomy. For example, Joshua noted that his stubbornness gave him "drive and determination," and an ability to confront others, including healthcare providers, family, friends, and strangers, who doubted his abilities. In one study on rugby players with tetraplegia, researchers found that the players used strategies related to self-determination, participation, and self-identification to achieve autonomy (Van de Ven, Post, Witte, et al., 2008). Likewise, Joshua's self-proclaimed stubbornness was a tool of self-identification and self-determination that he used to increase his and other's perceptions of his independence. Joshua reflected that he was "raised to be stubborn," citing the influence of his family on the development of his internal characteristics.

Like stubbornness, resiliency was an obvious characteristic of both Joshua and his family. One study that included family members caring for a relative with a spinal cord injury or traumatic brain injury found that those families with higher resilience had a more positive affect and reported less negative affect and caregiver burden (Simpson & Jones, 2013). Kilic, Dorstyn, and Guiver (2013) considered the factors that determined resiliency. They found that psychological distress and self-efficacy were the only two variables that were unique contributors to resiliency and that being resilient was an important psychological process when it came to long-term spinal cord injury management. Resiliency can be established through rehabilitation interventions including mood management as well as self-efficacy beliefs. Joshua's own characteristic of resiliency may have been a natural development from his interactions with his resilient family.

Joshua expressed that he was highly satisfied with his life despite his disability, which is a phenomena that is well supported by other research. Hammell (2004) reported high quality of life of many men and women with injuries between C1 and C4. The participants in that study also recounted similar themes as Joshua of autonomy, meaningful use of time, and supportive relationships. Anderson, Vogel, Willis, and Betz (2006) noted that of one hundred sixty-six participants who had sustained their spinal cord injury at eighteen years or younger, 48% reported they were satisfied with their life, and 84% continued to be satisfied at later interviews. Joshua exhibited a positive attitude with most situations, which may be more characteristic of those with pediatric-onset injuries versus people who experienced spinal cord injuries later in life. Although Joshua may have experienced depression immediately after the accident, he reported none as he recounted his adolescence and young adult years. In a large study on depression after spinal cord injury, researchers found that the prevalence of depression was higher one year post injury as opposed to five years, and in those between the ages of 35-55 years old at the time of injury, among other characteristics (Arango-Lasprilla, Ketchum, Starkweather, Nicholls, & Wilk, 2011). Joshua's pediatric-onset may have helped him to develop a positive outlook on life and avoid major depression. He also attributed much of his positive outlook to his faith, similar to a study by Chlan, Zebracki, and Vogel (2011) who found that more than half of their participants with spinal cord injuries relied on some sort of faith-based coping mechanism.

Joshua expressed a personal value for setting and achieving goals, which was clearly connected to the significance he placed on maintaining autonomy. He made specific, personal decisions in order to achieve his goals. For instance, he stated that he chose not to have a girlfriend in order to focus on his business. He chose to use only a few electronic aides to promote his autonomy, given the expense of technology and his high level of personal support (Verdonck, Chard, & Nolan, 2011). He chose to go back to school and use that new knowledge to create his own business. Heckhausen, Chang, Greenberger, and Chen (2013), found that having educational goals created better outcomes compared to those who had career oriented goals directly out of high school when it comes to the general population, but this was not the case for Joshua; instead, he directed his own career path to becoming a business owner.

Joshua has demonstrated a successful transition to adulthood. He has been able to achieve employment and business ownership, and has high life satisfaction though he is not able to live independently. Anderson, Vogel, Willis, and Betz (2006) concluded that those who experienced a spinal cord injury at 18 years old or younger can achieve stable adult outcomes. The researchers found that some of the factors for stability in adulthood included physical independence, mobility, occupation, independent living, and cognitive independence. Joshua has been able to make the transition to stable adulthood, despite continuing to require considerable physical support.

Clinical and Community Implications

While much is known about the functional outcomes of persons with tetraplegia, little is known about the day to day life experiences of these individuals. Joshua's story may serve as a foundation for understanding the path of a person injured as a child, and their transition to adulthood. Pediatric occupational therapists working with newly injured children need to help the family to look ahead to the child's life with disability. School-based occupational therapists also must respond to the changing child and help them to make the transition to adulthood successfully. Therapists must capitalize on the physical and emotional support of family, peers, and medical professionals. Joshua's strong relationships with his peers, who often served dual roles of friend and caregiver, provides a good model to accomplish this.

As a functioning member of society, Joshua has much to offer the community of individuals living with a disability. He is a model of successful transition to adulthood with a disability, including education and employment. Many professionals, including occupational therapists, vocational rehabilitation specialists, and social workers may benefit from referring to Joshua's story as they assist the newly injured into new life roles. Joshua also exemplifies strong interpersonal characteristics such as a positive attitude and resiliency, that some may not view as characteristic of people with disabilities. Joshua's unquestionable satisfaction with his life may serve to squelch some stereotypes of life with a disability, and thus provide more opportunities for people with disabilities in the community. People with disabilities can and should advocate for themselves in regard to accessibility, expectations of how to be treated, and achievements they may accomplish despite what others may think. Persons who experience an injury resulting in tetraplegia may be able to relate to Joshua's experiences and find that they may also be able to use similar techniques, shape their lives based on what they enjoy, and be introduced to new occupations.

As an occupational therapy student, this research has allowed me to understand how a person with a disability in general should hope to be viewed. Joshua has shown me that he, as well as others, hope to be viewed with respect and potentially as an knowledgeable or authoritative subject when it comes to business. I will not place limitations on my clients. I hope that I will be able to see the potential in my clients and not tell them they cannot do something. I want my clients to know that if they put their mind to it, they can make it happen; it just may mean that we all have to get creative. I respect the fact that Joshua wanted to work hard to do lots on his own, but as a healthcare provider for someone in need, we should all be supportive and resourceful.

Limitations

This study was limited by having a single participant that was well known to the researcher prior to the study. Adding the perspectives of more participants, possibly some with very different experiences, would increase the depth and range of the information and would allow for more clinical and community implications. The data would have been richer as multiple viewpoints and experiences would have been shared.

Because the participant was known to the researcher prior to the study, bias may have been present prior to interview. This was addressed as much as possible through journaling and discussing possible biases with peers and advisors. Other potential limitations due to the researcher's previous knowledge of the participant could have included the participant's willingness or lack of willingness to open up to the interviewer and share certain moments in his life. The researcher considers herself good friends with the participant, but not well enough to assume a medical role with him as his family and other friends will.

Future Research

Few studies have examined this population so opportunities for additional research are plentiful. This study should be repeated with additional participants with pediatric-onset spinal cord injury. Another topic of study should be attitudes and resiliency among this specific population.

Summary

The purpose of this narrative case study was to understand how a young man with pediatric-onset tetraplegia described his life experiences during his upper teen and young adult years. Data was obtained through two individual semi-structured interviews and observations. Interviews were conducted, recorded and transcribed by the primary investigator at the home of the participant. The participant provided information about his life including his experiences with family, friends, and healthcare providers. Six themes that emerged from the data included I *always have someone with me, I'm not easily broken, I'm stubborn, I've made it the best I can make it, I'm just like everybody else,* and *Right now it's about me doing what I want to do.* Results showed that the participant and his family viewed his experiences as typical, but they were actually rather unique. This included never being able to spend time alone, having to use adaptive equipment or transportation, and having a positive attitude about most situations including his ability to find ways to make things work. This research has provided future and current researchers, healthcare providers, families, friends, and other persons with spinal cord injuries insight on one young man’s life experiences in order to increase the understanding of this population.

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Appendix A

Informed Consent Form

Consent to Participate in a Research Study

The Description of Life Experiences of a Person with an Upper Level Spinal Cord Injury During their Upper Teen and Young Adult Years: A Qualitative Case Study.

Why am I being asked to participate in this research?

You are being invited to take part in a research study about understanding the life experiences of a person with a spinal cord injury. You are being invited to participate in this research study because you fit the criteria of having experienced an upper level spinal cord injury and are the appropriate age for this particular study. If you take part in this study, you will be one of about one to three people to do so.

Who is doing the study?

The person in charge of this study is Kelsey Yarberry, OTS at Eastern Kentucky University. She is being guided in this research by Dr. Dana Howell, PhD, OTD, OTR/L. There may be other people on the research team assisting at different times during the study.

What is the purpose of the study?

By doing this study, we hope to learn about the life experiences of a person with an upper level spinal cord injury during their upper teen and young adult years. The anticipated benefits will aid families, friends, healthcare providers, and other people who experience spinal cord injuries will be able to better understand living with spinal cord injuries. Awareness of possibilities can be raised and more knowledge will be gained in regards to life experiences of a person with spinal cord injuries.

Where is the study going to take place and how long will it last?

The research procedures will be conducted at your home or at a private place that is convenient to you. The researcher will meet you for an initial interview that will last approximately 60-90 minutes. Two to three follow up visits may take place depending on if the researcher needs to ask more questions or confirm acquired information. The total amount of time you will be asked to volunteer for this study is 5 hours over the next year (May 2013-May 2014).

What will I be asked to do?

You will be expected to set up a time with the researcher to come to your home for an initial interview. Upon arrival, you will be interviewed anywhere between 60 and 90 minutes. During this time the researcher will record your interview and take notes of their observations. Once your time has concluded the researcher will begin to analyze data, possibly coming up with more questions. The researcher may also complete a portion of the data analysis and ask that you check to see if the data is true. The researcher will meet with you in person at least once. Follow up visits may be in person, over the telephone, or through email communication.

Are there reasons why I should not take part in this study?
If you are non-verbal you should not take part in this study. You must be over the age of 18 and have an upper level spinal cord injury. Your place of residence should be in Kentucky. If you do not fit this criterion, you should not take part in this study.

What are the possible risks and discomforts?
To the best of our knowledge, the things you will be doing will involve minimal risks. Although we have made every effort to minimize this, you may find some questions we ask you to be upsetting or stressful. During the interviewing process, you will be subject to deep and personal questions which may stir up negative feelings or emotions. You may feel uncomfortable with certain questions asked and may choose to not answer. If you do get upset or stressed, we can tell you about some people who may be able to help you with these feelings.

You may, however, experience a previously unknown risk or side effect.

Will I benefit from taking part in this study?
You will not get any personal benefit from taking part in this study.

Do I have to take part in this study?
If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don’t take part in this study, are there other choices?
If you do not want to be in the study, there are no other choices except to not take part in the study.

What will it cost me to participate?
There are no costs associated with taking part in this study.

Will I receive any payment or rewards for taking part in the study?
You will not receive any payment or reward for taking part in this study.

Who will see the information I give?
Your information will be combined with information from other people taking part in the study if you are not the only participant. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University

Can my taking part in the study end early?
If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

What happens if I get hurt or sick during the study?
If you believe you are hurt or if you get sick because of something that is done during the study, you should call Kelsey Yarberry at (859) 760-6719 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your child's care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?
Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Kelsey Yarberry at (859) 760-6719. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project.

____
Signature of person agreeing to take part in the study Date

____
Printed name of person taking part in the study

____
Name of person providing information to subject

Appendix B

Additional Consent Form

Additional Consent to Participate in a Research Study

The description of life experiences of a person with an upper level spinal cord injury during their upper teen and young adult years.

Why am I being asked to participate in this research?

You are being invited to take part in a research study about spinal cord injuries by a family member or a friend who is a student at Eastern Kentucky University in the Occupational Therapy Department.

You may feel an obligation to participate in this research because you have been approached by a family member or friend. This additional consent form is to assure you that you have no obligation to participate. Your non-participation will not affect your family member (friend)'s grade or ability to contribute to this research. We have other resources for recruiting participants who are easily accessible to your family member (friend).

If you have questions about the study, you can contact the investigator, Kelsey Yarberry, OTS at 859-760-6719. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project.

____

Signature of person agreeing to take part in the study Date

____

Printed name of person taking part in the study

____

Name of person providing information to subject

Appendix C

Interview Questions

Interview Questions

In what way does your attitude affect you on a day-to-day basis? Over your lifespan?

What milestones are most significant to you?

How do you measure your satisfaction in life?

What are your biggest accomplishments?

What are your current goals?

What are your current interests?

Do you feel like you are living a fulfilled life?

Do you feel like you're missing out on any certain aspects of life?

What turning points have been made in your life?

In what ways are you socially involved?

What are your emotions on a day to day basis?

How do you perceive your future?

Is the face you presents to everyone else is the same as how you really feel?

> If not, why?
>
> What types of emotions do you tend to hide?

With whom are you the most comfortable to be yourself?

In what ways are you intimate with others?

Do you desire other types of intimate relationships?

In what ways do you express love?

In what ways do you receive love?

How do you express yourself sexually?

Is family a big part of your life? How?

In what ways has your family supported you?

What do you perceive for your family in the future?

Interview Questions (Follow-up)

How old are you?

How did you come up with your business idea?

What do you consider a “successful” business?

Why can you run a business so easily?

What do you mean when you say you realized it’s not something you wanted to do with your entire life? Why?

Can you give me a description of how you go hunting?

Can you give me a description of how you go fishing?

Do you drive?

Do you have ways to let out anger?

How are you at expressing your feelings, not just how you feel about others, but how YOU feel?

What made you into the sports enthusiast you are today? Do you play fantasy?

Where did your love of music come from?

Is this a brother bonding time?

What kind of care does your nursing staff provide?

What might happen if no one were with you? Breathing?

What else can you do independently besides TV, computer, moving your chair?

Can you tell me about your transitions in high school? Things you needed in school or elsewhere to do what you wanted/needed?

What about form high school to working?

Working to College?

What do you see as being the biggest difference from high school to now?

(These can include staff, AE, goals, etc.?)